

Kylie Ralston: Stroke, Bulgaria, and the Friend Who Flew Across the World

Next of Kin After Stroke: When Your 19-Year-Old Has to Decide For You

Kylie Ralston was 56, living alone in Sofia, Bulgaria, and getting back into shape after a divorce. Three mornings a week she ran. On the morning everything changed, she was doing a local park run with her friend Rebecca when she slowed to a walk, then tried to run again and couldn't. "It was like the message wasn't getting through from my brain to my legs," she says. No headache. No fatigue. Nothing that felt like an emergency. She finished the run, registered her time, and went home. It wasn't until she collapsed getting out of the car that anyone understood what was happening.

By the time Kylie reached hospital, she had suffered a left frontoparietal haemorrhagic stroke, a spontaneous brain bleed roughly 7.5cm across, with none of the usual risk factors. No high blood pressure. No cholesterol history. No aneurysm, no AVM. She was placed in an induced coma for four days. When she woke, she couldn't move her right side, and she couldn't speak.

What "Next of Kin" Really Means When a Stroke Hits Abroad

Kylie was a permanent resident of Bulgaria, not a citizen, divorced from her daughter's father, and living on her own. When the hospital needed someone to authorise emergency surgery, there was exactly one person available to make that call: her daughter, then 19 years old, splitting her time between her separated parents' homes.

It's a detail easy to skim past, but it sits at the centre of this episode: next of kin isn't a role most of us think about until a hospital needs an answer immediately. Kylie hadn't nominated her daughter out of any formal planning process; it simply fell to her, because she was the only adult relative in the country who met the age threshold.

A 19-Year-Old Signing Consent-to-Operate Forms

Kylie's friends contacted her daughter directly. She rushed to the hospital, and unconscious, unable to advocate for herself, her mother's care now depended on decisions made by a teenager under enormous duress. Kylie's first memory afterward is her daughter arriving in the ICU in a hairnet and scrubs, holding her hand, telling her she loved her.

It's the kind of moment that rarely makes it into conversations about stroke recovery, because the focus so often lands on rehabilitation milestones: walking, speaking, returning to work. But before any of that, someone has to be legally empowered to say yes to surgery, and for Kylie, that someone hadn't expected the responsibility for another few decades.

The Gap Between Acute Surgery and Real Rehabilitation

Bulgaria's acute care, Kylie and her friend Nicole Nott both stress, was world-class surgery within roughly two hours of the stroke, the kind of outcome her friends still describe as a miracle given the size of the bleed. What came next was a different story. In the public hospital, physiotherapy visits totalled two sessions. There was no speech therapy. After 14 days, still unable to move her right side or speak, Kylie was expected to go home. Her partner, Guido, refused to accept it, and the couple began privately funding rehabilitation themselves.

This is a distinction worth sitting with if you or someone you love is navigating stroke recovery in a country or even a region with limited public rehab funding: acute survival and functional recovery are not the same fight, and they are not always resourced the same way.

When a Friend Becomes the Rehab Team

Nicole Nott, an occupational therapist and Kylie's friend since they were 16, found out about the stroke through a message she initially suspected was a scam. Within days she'd cleared her schedule and flown from Australia to Bulgaria. What she found in the private rehab hospital was a caring but under-trained care team, kind staff with, as Nicole puts it, "no rehab expertise."

Nicole spent close to two weeks restructuring Kylie's room and routine around basic stroke rehabilitation principles: approaching from Kylie's affected right side to address her spatial inattention, built-up cutlery to force use of her weaker hand, a balloon tapped back and forth for shoulder strength, word games layered on top for speech practice, pegs and curtains repurposed into arm exercises. She also pushed back hard against hospital staff who tried to stop her from helping Kylie transfer to a shower chair or toilet, at one point being told outright she wasn't permitted because she was a woman. Her single goal before flying home: get Kylie toileting independently again, for dignity as much as mobility. Kylie called her from Dubai airport, mid-transit, to tell her it had happened.

Living With Aphasia

Fourteen months on, Kylie's right-side weakness has largely resolved. What remains, she says, is the hardest part: expressive aphasia. "I can't express myself like I used to." It's a small, telling detail of the condition that even the phrase "I can't" is itself shaped by the aphasia; the words available to describe the loss are affected by the loss.

The Unexpected Gains

Both women point to what came out of the crisis alongside the hardship: Kylie's relationship with her daughter deepened. Her circle of friends in Bulgaria proved itself in ways she hadn't anticipated. And in the rehab hospital, her partner Guido proposed something; he told her he'd already decided before the stroke but simply hadn't gotten around to asking.

If this episode raises questions about who is legally positioned to make decisions for you and whether that person actually knows it, it may be worth a conversation with your own family before a crisis forces the issue.

For a deeper account of navigating identity, recovery, and unexpected transformation after stroke, Bill's book *The Unexpected Way That A Stroke Became The Best Thing That Happened* is available at recoveryafterstroke.com/book.

If this show has helped you, you can support it at patreon.com/recoveryafterstroke.

This blog is for informational purposes only and does not constitute medical advice. Please consult your doctor before making any changes to your health or recovery plan.

Kylie Ralston: Stroke, Bulgaria, and the Friend Who Flew Across the World

When Kylie had a stroke abroad, her 19-year-old daughter became her next of kin, and a friend flew in to help her recover.

Bill's Book: *The Unexpected Way That A Stroke Became The Best Thing That Happened*

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Introduction - Next of Kin After Stroke

Bill Gasiamis (00:00)

And one of my first horrible thoughts was, is this a dreadful hoax? Is someone, you know, is this some horrible scam? And it made me feel quite sick actually And then I rang her son who lives in Australia and he's like, Yeah, I'm so sorry. I haven't told you. Yes, it's true, mum's had a stroke.

Bill Gasiamis (00:16)

Welcome back to Recovery After Stroke. I'm Bill Gasiamis, and today I'm joined by two guests, Kylie Ralston and her friend Nicole Nott. Kylie was 56 living in Bulgaria when she suffered a left frontoparietal hemorrhagic stroke, a spontaneous brain bleed with none of the usual risk factors.

Nicole is an occupational therapist and one of Kylie's closest friends since they were teenagers. And when she found out what happened, she got on a plane to Bulgaria to help. In this episode, we get into what it means to have a stroke far from home in a country where you don't speak the language, and public rehabilitation funding barely exists. We talk about who becomes your next of kin when you least expect it, what it's like to advocate for a friend inside a hospital system that won't always listen.

And what recovery actually looks like 14 months on, before we get into it, if you want a deeper look at identity, recovery, and unexpected transformation after stroke, my book, *The Unexpected Way That Stroke Became*, the best thing that happened, is available at recoveryafterstroke.com/book. And if this show has helped you

And you can support it to keep me on the path of getting to a thousand episodes, you can do so At patreon.com/recoveryafterstroke

Bill Gasiamis (01:37)

Kylie Ralston and Nicole Nott, welcome to the podcast.

lovely to be here, Bill. Thanks for having us, Bill. Kylie, tell me a little bit about what life was like before the stroke. I was very active and I had a full life and I was working full time. and I was living in Sofia in Bulgaria, in my on my own, in my own apartment. I was renting, actually.

and I was getting back to fitness. So I was g getting I was running regularly. So two two or three times a week I was hitting the gym and hitting the tr the treadmill. And that had been happening for like a few month like six months or something like that. but before that I was very fit and active. What kind of work were you involved in?

I was a HR work. I was a ha HR leader and so I had my own consultancy I had a team of people that I've managed.

I had thirty five people, so and that they were people in Germany, Poland, Czechia, Portugal, France, so everywhere in in Europe, basically. Yeah. Wow, how how does an Aussie end up in Bulgaria with staff or clients in that many

countries? short answer is I came here with my family, so with my ex husband. and shortly after I arrived we separated and and ultimately got divorced. and I stayed on because my daughter is here. So she was only eleven at the time and I could just couldn't leave her.

The Day of the Stroke

So you were living at home with your daughter? she was sharing her time between between us both. Yeah. got it. Okay. So both parents are there. So your daughter was going backwards and forwards. On the night of the stroke or on the day of the stroke, can you take us through that? What were you experiencing? Was there anything unusual that happened that made you think something was wrong? How did it go down? I was with my friend Rebecca.

And she was running ahead of me as she she was faster than me, so sh and she often often ran ahead of me. and I'd slowed down to a walk and when I started to run again or try to run again, it it was like the message wasn't getting through from my brain to my legs. And I thought, that's strange, that's that's really odd. 'Cause I didn't feel like tired or

anything and I didn't have a headache and well stuff like that. and I just walked through the rest of the park run. And then when Rebecca saw me coming to the finish line, she waved me over and she said, come on, let's go register your chip. and so I did that. and she said afterwards that

there was a little bit of fumbling with with my phone and there's a there was a

little bit of fumbling when I put my jacket on, but other than that, I just seemed exhausted from a run. do you recall after the experience of feeling exhausted from the run where you ended up? Did you need help?

Yeah, I do. So so she didn't notice that I wasn't talking because I n I'm normally an endless talker, so I she didn't notice that I wasn't talking. And she said that that that is one thing that should have alerted her to what was happening. but it it didn't. And so I'd caught the bus to the park run and her husband was there and so he drove me home.

And I j I remember the journey home and when when we when I went to get out, I just couldn't. And so and Mark came around to my side of the car and help tried to help me out and I just collapsed against him. And so then that so then they said, quick, something's wrong something's I don't remember what they

They they said, you know, they basically took me straight to the hospital. Yeah. And also rang Guido, my now fiance, but my partner at the time. Uh-huh. So you you went from the run, attempted to go home, and then from that attempt to get you out of the car, actually into your home, it was pretty clear that that wasn't gonna happen and you ended up in hospital. so

Did you guys drive to hospital? Do you recall that? Yes. Yes. We do how far is it from your home? it's pretty close. I don't know about kilometres or time, but it's but it's like ten or fifteen minutes. Yeah, so it's not too far. But they didn't know what was going on, of course. They just knew something wasn't right and then they figured one of the best things to do is just get it to a hospital. You get to the hospital

Do you know what happens after that? Do you get admitted? do you get tested for anything? I suppose what I'm asking is when is the first time you realise that that you've had a stroke? When do they report that back? When I came out of the coma. So I was put I was put into an an induced coma straight away. so I I obviously don't remember anything of of that. and but Rebecca's told me afterwards.

so she's filled in the f filled in the filled in the blanks for me. and by that stage her husband thought it was a stroke. So she's he said he said to the staff at the hospital, we think she's having a stroke. And so yeah. So how long were you in the coma, do you know? Has somebody told you how long it was? Yeah, four four

days.

Four days, okay. And do you know what kind of stroke you had? Yep. I had a left Frontoparietal hemorrhagic stroke. Wow, that's a good effort. So you had a brain bleed. Yep. Do they know what caused it? No. It was spontaneous and I didn't have any of the risk factors. So I didn't have high blood pressure, a history of high blood pressure, but admittedly I'd hadn't tested my blood pressure immediately before the stroke. but you know

That's un that's unlikely to be the cause. And I didn't have a hi a history of high cholesterol. and so they just and I didn't have an aneurysm and I didn't have like what's the other thing? The An AV AVM. AVM, yeah, I didn't have any of that. And how old were you? Fifty six. Okay. So you had a spontaneous

Bleed in the brain. That happens. People do have that happen from time to time. And sometimes they don't have any symptoms leading up to it or anything like that. and this is the bizarre nature of like there's an unlimited number of ways, unfortunately, for people to have a stroke. Now, you woke up in hospital four days later. What kind of deficits did you have? I couldn't move my right side and I couldn't speak. Okay.

Now I've got an idea of well, I haven't got an idea, but my mind immediately kind of says like if you're in hospital in Bulgaria, that's not a hospital in Melbourne. That's not the Royal Melbourne hospital where no shit is unreal, like it's perfect and it's got the highest technology and it doesn't matter how many things we can bitch and moan about the system being here like compared to Bulgaria, my expectation is that we're world class.

Perhaps that's not the case in Bulgaria. Would you agree with that statement? I would have agreed before and my my my expat friends here would have agreed before, but now we're all saying maybe Bulgaria is better than we thought. That's brilliant. Awesome. Okay, so

Rehabilitation Challenges in Bulgaria

As far as like medical interventions and all that type of stuff, you felt like that was handled like any other world class hospital would have handled it. Yeah. In that in that s it in that stage it was. but there's no like that was a public hospital and

there's no there's no public funded rehab after.

or or very li very little. So so that's where that's where Australia is ahead. So when you knew you had deficits, was there any rehabilitation whatsoever? Did you get any of that while you were still in hospital? Minimal. So the the physio came to see me twice. and so that's so that's all and I got no speech therapy and stuff like that.

and but when I was discharged from the public hospital here and went and so they they expected me to go home from the public hospital. And so Guido said she just can't like like what what the fuck? After how many days? After how many days, how long? Fourteen.

Wow, your right side was still offline and you still had problem. Yeah. Okay. So we we just paid for paid for private rehab. got it, right. Yeah. And how long were you in private rehab for? another like two months or something like that. Right. Okay, that's pretty cool. So i even though you couldn't access it publicly, you were still able to

Access a private now. Are you a citizen in Bulgaria? Not a citizen, a permanent resident. Okay. So do you have are you as a result of the fact that you're a permanent resident and not a citizen, do you have different things that you are able to access because of your status? No. no. I'm it's I have the same rights as a citizen. The only one the only right I don't have is

I'm I'm not able to vote here and I'm not I'm not able to work in other EU countries. Got it. Okay. So that's pretty traumatizing, the whole experience, and then to have to deal with overcoming your left side and your speech deficits after the two month mark, roughly where were you at where you where you are now? Because you kinda sound pretty good. Okay.

No, yeah. no and and the other thing the other thing that I must say about Bulgaria is I don't speak Bulgarian. very very little. So that was a problem. Yeah. I can imagine, yeah. so maybe you can come in here, Nicole, and and talk about where I was at when you came to see me, because that was very very very early on in my

in in the private rehab hospital. Yeah, Nicole, tell me a little bit about what it's like to receive a phone call to find out that your friend has had a stroke. I was

absolutely hellish. the way I found out is I got a message through social media from someone saying, Hey, I'm a friend of Kylie's and she's in hospital in Bulgaria.

And one of my first horrible thoughts was, is this a dreadful hoax? Is someone, you know, is this some horrible scam? And it really, you know, it made me feel quite sick actually thinking this is that's not someone I know. It does look like a name I've seen in Kylie's kind of social media world. And then I rang her son who lives in Australia and he's like, Yeah, I'm so sorry. I haven't told you. Yes, it's true, mum's had a stroke. and I was kind of

beside myself because by training I'm an occupational therapist, but Kylie and I have known each other each other since we were about 16. and it was really hard to get the information that I wanted as a friend, but also as a health professional. I was wanting to understand what kind of stroke is it? Where is it? What's the rehab? What can we do? How's it going? And at that stage the information that I had was that

you know, it was really seriously affected the speech part of the brain and obviously the hemiplegia, the weakness down the right side and knowing that Kylie was right handed. so, you know, it's the friendship part that your heart's breaking and it's also the therapist part that's wanting the information to be able to, you know, reconcile it for myself, professionally what that was going to look like as a consequence for Kylie. Yeah, and you're so far away, so you really can't

do anything and kind of have to like take information second hand, third hand, and be kind of in a position which is really uncomfortable for, I imagine, a friend, but also a therapist, right? So as an occupational therapist, that's not the information you work on. You work on actual facts, scans, reports, like a whole bunch of things. So are you also playing it out in your mind? Are you kind of

Doom thinking it, like are you how does it affect you personally? I think for me I was all I was really very conscious of not stressing other people. So like friends, family, because sometimes when you are a health professional, you know, you have knowledge and information and you know, you sometimes you you're keeping that to yourself to some extent because you do know what can happen to people and you do know what consequences can be. So I was really trying not to ask too many questions of people as well.

but I was seriously desperate for information. And so I remember I'd gone to a

party and I didn't really want to go because I was actually, you know, upset and stressed for Kylie. And I did end up going to a party and during the party I was really kind of outside having a bit of a downer really by a campfire. but I got a phone call or a message to say that I think you'd

said some words, Kylie, and were kind of waking up. so you're still in the acute hospital then and that you'd been able to move your leg a little bit, I think. Yeah. And you know, joy in that moment. And yeah, I felt very, very far away. And then

What happens over the next few days? Like do you guys continue to communicate somehow? Do you keep getting information? Are you being updated? Yeah. Yeah. I wasn't able to get my into my phone or my any of my devices. So I wasn't able to able to because I couldn't remember my password, right? And so and and I tried like d

different ones and I you know I just got locked out. So and when I was able to get in then that made it it made it easier t because I was able just text short messages. So so Nicole and I kept in touch that way. and before

English-speaking

Before you came, Nicole, I think I was talking, but not not not as well as I am now. Yeah. So was it, Nicole, in your mind, you were always going to fly over to Bulgaria and beath your friend? Or did you guys have to work that out? Like what happened now? It's so cool that you get to have a somebody in your corner that is also a

Fred, but also a medical professional in the exact field that you're struggling with now. Right. Like how do you just drop everything and go overseas and be with your friend? Yeah, well, very grateful that I had an up to date passport. So that was that was a good thing. Kylie, it was interesting because the texting, like if I go back and look at that history, it's like you can see the progress in the texts. So you can see that Kylie

was using kind of more single words and having struggles with spelling and putting sentences together. And then over time, you know, they became more fluent. but the thing that happened was that Kylie and I were talking and she was able to you know, she got some speech back and we were talking. And she was just saying about the rehab care that the the the kind of caring staff

just seemed to have no rehab expertise. So the physios were amazing. I think they were great. There was no active speech therapy for Kylie. I think we ultimately found an English speaking speech therapist but who still had Bulgarian as a first language. And there's very few occupational therapists in Bulgaria, seems to be some expats. And Kylie was talking to me a jab about just

you know, really basic things like not being taken to the toilet. and that's probably what broke my heart. It's like I cannot leave her in bed, not being able to go to the toilet. I just can't do it. And so I just said to my partner, I think I just need to go to Bulgaria. And luckily I'm self-employed. So I just kind of cleared my schedule, got on a plane and yeah, I was just

I suppose I'm incredibly grateful to have the skill. incredibly grateful to have the financial ability to do it. and yeah, and the skills to do it. And you know, you don't always get an opportunity in life to do the right thing, or sometimes you don't make that decision and later you think, Why didn't I do X, Y, and Z? I try not to live my life like that. I try to actually do those things. So, yeah, I got on a plane and

basically arrived at the airport, got on a train straight out to see Kylie at the Rehope Hospital. You're a real superhero. I'm very grateful to Nicole. Yeah. I rec you know, my story is kind of well, it has a similar kind of thread to it. I one of my best friends is a radiographer and he was a radiographer at the Royal Melbourne Hospital where

I was a patient for nearly two and a half years because I was in and out with a number of brain hemorrhages. I had three in total in the same spot, but over two and a half years, then I had brain surgery. And I can't tell you how many scans I had, but being a radiographer, he was the one who was in the room taking the photos through the MRI. Yeah. And then he would come out.

And he would tell us what he saw in the RI, which was against the rules. that's why I won't name him. But but that meant that we didn't have to wait a month to get our results and the the meeting for the results was just more of we'll go through the process and and have the meeting. Yeah. And and and it was like and I regretted my life

when at school I used to throw his books on the roof of the canteen just to mess with him going to s to class late to get in trouble. and I've apologised profusely for

that and thanked him every day for the fact that, you know, he was able to lend his well, you know, he was able to be in the room. He was able to have that conversation with us and he was able to ease our minds.

over that two and a half year period and then you won't believe it. Like his daughter had an AVM at seventeen. And she went through that and and has recovered from that somewhat now in the last few years. and I got to be I mean I hate that I had to be this guy, but I got to be the guy that supported him through that really acute phase and

There is just nothing to describe what it's like to be able to repay the favor. and then but B, when I was in that situation to have somebody kind of well, you know, like put their arm around me and really walk me through every stage. Me and my wife and my family walk us through every stage of that part of it, other than intervening as a brain surgeon. But he was the one that put us in char in in touch with my brain surgeon. like

Everything that happened was just the most amazing experience to be able to be guided like that. And I know it's a privilege and many people don't get that opportunity. so I see Chris, I haven't told him this in person. I see him as like a bit of a superhero, but he doesn't know that. I've told him I love him in the way men tell each other that they love each other by s abusing him and swearing at him and telling him that the team that he follows is terrible and all that kind of stuff.

Reflections on Healthcare Systems

so you arrived in Bulgaria. take me from the airport to the hospital. Like what happens? How is that? Actually the flight was really good. Customs was pretty easy. There was some annoying folk in front of me who I wanted to punch in the face and tell them to hurry up, but I was just, you know, needed to to get there. Kylie's daughter met me at the airport.

And then we got the train together out to the hospital. So, you know, obviously I'm seeing my first sight of Bulgaria. I'd never been there before. so not really taking a tourist route at this point. so went out to see Kylie. And, you know, when you just eyeball someone and I, you know, just thank God I'm here, I'm in front of her. Her she'd had a shaved head. she had some pretty spectacular surgical scars, a couple of very big scabs still on her head.

she looked skinny, she looked pale, she had started doing a little bit of movement and the hospital room was really kind basic and crazy. Her friends had funded a pressure mattress for her that didn't exist. And some of these things I had been liaising with Kylie's friends in Bulgaria about what could we do, how you know, what do we want to prevent? So we want to prevent anyone pulling on from.

Her weak shoulders and like don't let anyone pull her by the arm. this is how I want, you know, to help her with posture in bed or in sitting. and you know, like speaking in single kind of actions at a time and just take your time, say something, wait, wait, wait, wait, wait. Just allow Kylie's brain to, you know, take that information on board. Don't speak for her. and when I got there, it was really clear that.

She had an inattention to the right hand side as an effect from the stroke. So then I was a bit of a ball breaker, rearranging the whole room. No, no, no, no, no. Where, you know, everyone come from the right, everyone sit on the right. no cutler, you're not allowed to have your phone in your left hand, you're having your phone in your right hand. I'd taken some things with me from Australia to Bulgaria that I thought she might need. like some built-up cutlery, because I wanted her to use her right hand to feed herself. I took a couple of

kind of activities that I thought we could do to look at some retraining for the right arm. what I'll still bring with me, try to remember now. Benjamin. So yeah, just try kind of going into early stroke rehab principles. Yeah. Did you go there well you went there as a friend. But when you were there, were you able to be a professional and also have a conversation with the local team?

Kylie and I laughing. Do you want to tell that story, Kylie? Which one are you thinking about? Where I got told off. No, I don't remember that. well, Kylie was in act like, you know, there was still quite a lot of weakness, but she was also so determined for her own rehab. And in the system there their carers really don't have a rehab focus. They have a

I'll provide you a meal focus and I'll occasionally do some cleaning and I'll occasionally change the bed linen and but really not a rehab focus. So I've personally found it quite easy to help Kylie to like stand move. And so the very first weekend I was there, it was a long weekend and what I didn't realise later was that they were actually quite understaffed.

Which worked in our favour because I was helping Kylie to get onto a shower chair, taking her to have a shower, us taking her to the toilet, because prior to that time they were just, you know, using pads for toileting because Kylie couldn't stand up or move on her own. And because I'm trained, I found it very easy. She's a lightweight person and she and I just work together and I could do that. I think it was the Tuesday,

person who I refer to as Nurse Ratchet. remembering now kind of intercepted me bringing Kylie back from the bathroom to her room and just like, nope, nope, nope, nope, nope, nope. What are you doing? Stop that, stop that, stop that. and you know, she and I are having a bit of a discussion. And basically she's refused and I'm allowed to move Kylie. So Kylie is sitting out in the corridor. I think I'd luckily kind of covered you up for privacy.

and she's like, No, you're not allowed to move her. I'm gonna go and get the physio. I think at least forty minutes went by and then she comes back, well, okay, and I said, Look, I am a trained person, it's easy, it's safe. no, I'll think about it. And then after I think another fifteen minutes she pushed your chair into the bedroom. And then I think it was probably another fifteen minutes where she just decided to move Kylie herself at that point.

even though that was out of policy and the physios had to do it. And then it was all this discussion with me that you can't do it. And in the end it was you can't do it because you're a woman. Not strong enough, you know. so yeah. Then Kylie and I kind of would go on clandestine missions because again, from a rehab point of view, being able to stand transfer, it's putting all the weight through the leg, it's giving feedback to the brain. I really wanted to make sure Kylie's bladder and bowel were gonna work properly.

And you know, sitting in bed and that's just not ideal. So then Kylie's like, Nicole, I want to go to the toilet. I was like, I'm banned, I'm banned, Mother Nurse Ratchet, I'm not allowed to take you. And I was like, shit. So I would go on a little mission, go look down the corridor, make sure she was nowhere to be seen. And then I quickly stole the shower chair and then I found a bucket. And so Kylie and I were doing

secret Wii missions in the bedroom. until w on one of our missions I just hadn't quite got the bucket in the right place. And so then I it was also then later on a

cleaning mission. So it was it was a pretty crazy environment. yeah, just for that lack of the whole team approach to rehab. Whereas, you know, in Australia the nurses would all be rehab trained. They would be transferring someone

physios would come in, speech would be coming, OTs would be coming. So I was kind of desperately trying to convince Kylie or to get her rehab to a standard where she'd be able to come back to Australia to get some more rehab. You know what's good about this conversation other than the hilarious nature of it also is that

I as an as a person who hadn't had a stroke before my hadn't known anyone who had a stroke before my experience, if I had come across somebody who had had a stroke, I wouldn't have known what to look out for and what to say to support them in a situation where perhaps something was being neglected. Because I don't know what I don't know. I'm not a professional, right? Just like those nurses and therapists that weren't specifically trained.

Yeah. In certain things. I mean, you may as well be not only talking a different language, but you may as well be making it up as you go because as far as they know, now this is what we do for stroke patients. This is how we handle that. is it a lack of understanding of what stroke rehabilitation requires, or is it a lack of resources, or is it a little bit of both? Do you feel in Bulgaria when you were there?

I think I think it's a lack of of all all of that but it's the lack of maybe money. So it's a lack of training. So there's there's not enough there's not the the nurses or the orderlies or whatever they're called here, are are aren't paid very much. So they so

And it just like, even though I was in a private rehab hospital, so you would have expected that more. It's you would have expected more, but I just think that they just don't have the money to to train those people. Yeah. it wasn't really a role, was it, Kylie? Like they really were more like housekeepers in a sense. It was more like cleaning a meals.

I have to say the physios were excellent. and a lot of the physios had good English as well, which was for your rehab was so important. because again a lot of the carers they would come into the room and you know, again, just from a speech therapy point of view, in Australia, say if someone came into the room who was

the person who did the menus or filled up the water bottles or the cleaners, Kyler could have spoken to all of those people and had

incidental communication the whole day in English. But because of all of those p incidental people coming in didn't speak English, you know, reasonably in Bulgaria. it just for me, I was worried about the lack of just exposure to English language as well. So not even speech therapy, just incidental language through the day. Which is very helpful and people don't realise how helpful it is to be able to speak to a nurse about how you're feeling or what's happening.

Yeah. And all the usual stuff. And Kylie's chatty and friendly and she would have just been having conversations galore, but it just it it it couldn't be. Yeah. Yeah, it's another another barrier. so you know when you go overseas, it's your friend and you're a professional. How do you handle that? Because you know, like are you emotional? Are you trying to put a lid on it? Are you allowing yourself to

Gonna be emotional. How does that work? We had some killer laughs, didn't we? I mean, I'm a joker anyway. And so, like the first time Kylie got to do a poo on the toilet, I just did a poo dance for her. So I I felt half my job was you know, cheering her up and keeping it light and having fun and chatting about stuff we would just always chat about.

as well as doing as much rehab because it was very exhausting because, you know, p after a stroke, it's very fatiguing. you know, so to Kylie was really tired and needed lots of rest. So and because I had just you know, obviously dropped tools to go over quickly, I was just working sometimes. So I just have my computer and if Kylie was asleep I'd just stay with her and and her partner Guido as well, who was there with her as well. So just, you know, emotional support wise. But

Yeah, I do some work. And I stayed in Kylie's apartment. So I w was I just stayed at her place and I I train out to see her each day at the hospital. W how many hours would you spend in hospital with her? What do you think, Kylie? you would often arrive at like ten in the morning and you wouldn't go till like five in the evening or six in the evening. Yeah. So technically visiting hours kind of finished at six.

So I just try and stay most of the day. A full shift. Yeah. Yeah. Unpaid. Unpaid labour. Slave driver. Yeah. yeah. But nah. That's what friends are for. I very what I very much wanted to stay the whole day because I did really, really wanna like especially the toileting thing. I just really wanted that.

Setting Goals and Achievements

I had this bit of a goal for myself for Kylie that she would be able to take herself to the toilet before I left the country. So just from a dignity point of view, from a mobility point of view, transfers, you know, bladder control. So yeah, that was one of my big goals. And she rang me when I was in transit at Dubai Airport on my way back to Australia and said, Nicole, I just took myself to the toilet. Wow, that's cool. Yeah. Yeah. And and I was having

physio two physio sessions a day. So I was having other than Nicole. So I was having like about one session about of about an hour in the morning and one session of about an hour in the in the afternoon. Got it. You Kylie seem like pretty mm chill, pretty calm. how are you handling it though, emotionally? How's the aftermath

Treating you because there's a little bit of you know, there's all that acute stuff. It's awesome when your friend is there, but then your friend goes home, right? So how how does that transition kind of happen? Yeah, I might start crying. because I've just recently spent seven months in Australia. So I I went to Australia in October last year and I came back in just in May.

and I had more rehab there. So I had I had student led rehab at at first and then I got in got accepted into Birch, which is the brain injury rehab community and home in Ad in Adelaide. so that's that is is a whole team of people. So I had I had physio and I and a occupational therapist and a

a e exercise physiologist and a speech therapist and stuff like that so I th that's really good. now the most frustrating part for me is the aphasia so I I can't I can't express myself like I used to. Yeah. You know what I love about

interviewing people who have aphasia is when they say I can't in a sentence to describe something to me it triggers the part of the condition which doesn't allow the words to come out. It's so interesting. That happens so so often. And it's just a for me, I noticed this I'm saying it just from a perspective is maybe I can't is not

the right word. I don't know. You might remember this, you might not, but maybe I can't is not the right word. Maybe the right word is

Something that helps you get to the word that you need to get to. And okay, now that's just me, the uneducated stroke survivor on a phasia guy. Like I don't know about that. But it's so interesting, it happens every time. but then Nicole goes home, you go home, your partner is kind of now taking over the caregiving role, and you still have some deficits. phage is one of them.

what about your right side? How offline was it? I I also moved in with Guido after the after the stroke. So so that was that was a has was ha was and has continues to be a challenge because we're still getting used to living together because we weren't living together before. and I was very in very independent before.

And I was living in Sofia and he and he and I now live in a in a village. So I live in in a village just outside of Sofia. And I'm not driving yet. but I was medically cleared to drive in Australia before I left. So I'm going through the process here. so anyway, all of all of those things together make it very challenging.

don't get me wrong, I I I love him, but but you know, and and I d and and I made that decision because my apartment is was was on the fourth floor and th there was no lift. Wow. Yeah. So back to your question. When I was when I was when I came here,

when I was discharged, I continued with as an outpatient and and the physio continued to come at home twice a week. So I was having more physio maybe like five times a week. and like it were ha had started to come my right side had was all already

back online, but I would I was just working on building strength and

and I would get still very tired. Yeah. And did your daughter end up coming to live with you as well? No. but she she at the beginning she she was my next of kin. So at the ripe old age of nineteen, she signed the consent to operate forms. yeah, so that was that was very difficult for her.

I didn't know that at the time, obviously. but yeah. And did that happen, did she become your next of kin because your former partner, her dad, and you had separated and then his that role wasn't gonna be his anymore. It's just passed

down to the person who was the closest to you. Like how did that happen?

Family Dynamics and Support Systems

We're divorced. I I'm divorced from her dad. Yeah. So he's definitely not my next kin. Right. So that ha changed after the divorce and she was the only person you could nominate because she was over is there an age limit to the next of kin? Eighteen. Yeah. Okay. So she had hit that criteria, you nominated her and then at nineteen she got to make a decision.

Which she never and you never would have expected ever for that to be a thing. I didn't nominate her, it would just happen. So I was I I was unconscious at the time that she signed those forms. So yeah. So my friends actually contacted her. and she she rushed to the hospital. so it was all under duress. It was like this is what happened to your mum, you're her

Next of kin, whether you like it or not, you have to decide. Yeah. Far out. Okay, that's pretty full on for a 19 year old. Yeah. Yeah, seems like she did a good job. How did she handle this whole mum's not well situation, this stroke thing? Like how did she deal with it? she was very good. my first memory actually is of her

coming into the ICU with with the with the whole, you know, the whole like the the hairnet and the mask and the and the and the what's it called the scrubs. Scrubs, yeah. and she held my hand and said t that she loved me. so that was pretty special.

And incidentally I have an a another memory of Guido coming into the ICU as well and singing singing to me. So he he said that he said that I always wanted him to sing and he refused before. And so did did I want him to sing to me now? And I squeezed his hand or on the on the left he's was holding my left hand and I squeezed his hand and so he knelt down beside my bed and started singing.

Wow. Can he actually hold the tune or is he hard to hear? Yes, see he's he's very musical. Okay. Thank God. If my wife had asked me to sing a w if I had asked my wife to sing, it wouldn't have been a good experience at all for either of us. Yeah, he was he was a busker in i in his younger years. Yeah. and now he decided to come good. Fair enough. Well that that's important. You know, things like that are important. It lightens the the mood and it makes Yeah.

You kind of feel like your family's around and that you know you know, maybe kind of things might be all right. Like it gives that glimmer of hope. Is that how you received it? Yeah, I did. yeah, but I'm also very, very determined. So I'm a I'm a very normally very strong woman and so everyone said to me that if it well not to me, but

we had a we had a group WhatsApp chat so and I was added to it later and everyone said in that that if anyone can get through this, Kylie can. Yeah. So you know when you're told you've had a stroke, you wake up with all the deficits and everything. Are you like how do you take it? I woke up, couldn't use my left side. I I did not for one minute.

It did not cross my mind like for one minute that this is not a good thing. Like I mean, clearly I wasn't able to move, etcetera. But it never kinda went a lifesaver, I'm fucked. Like I never had that happen. Me as well. yeah. I I'd I've never thought that. I don't know whether I even thought that

It was n like you said, that was not a good thing. I just put one foot in front of the other and or not literally, but the Yeah. Metaphorically. Yeah. Metaphorically. so one foot in front of the other and just got on with it. Yeah. Nicole, like you come across in your work, you come across a lot of different versions of patience, right? Like you get people who

might just be by design more negative to a bad experience and then people that are half class full to a bad experience. Just from a professional perspective, what's the difference like when you're trying to rehabilitate somebody that has kind of that different mindset?

From perhaps what Kylie and I described.

Yeah, I mean I'm probably in the last half full camp as well. So as an OT, I suppose we always meet people where they're at. because everyone is a combination of their past experiences, aren't they? So and cultural things, like there's a very significant cultural differences in how people respond to pain or disability and expectations of kind of family and I suppose cultural expectations in Australia are even about

you know, what what what should be publicly available. So, you know, from an expectations point of view, I think a lot of it is based on, you know, previous

experience. So as a therapist, we're obviously there to support, you know, emotional well being, physical well being, and try and find the things for people that connect with them. So meaningful, like OTs are our absolute core is meaningful occupation. So how do we find something that's meaningful to that

person that we think is going to get them from kind of, you know, here to there and it's gonna be very different different motivators, you know. Kylie is probably, you know, very self motivated as described. Sometimes it's about people really have a d strong desire to get back to work, or people have a really strong family structure that they want to be able to get back to do something with their family. So

finding the way or the thing hopefully that's going to motivate them. But we certainly work with people who you know, have a high level of distress from what's happened to them and and on an ongoing basis. One of the things I've got a little quote on my desk that you can't see here, but it says, I'm still me, just a different version of me. And it's what someone one of my clients told me recently who has MS. and often we find need to find the new version of someone.

and the new meaning for someone if that, you know, needs to happen. So that's our great challenge, I suppose. That's a big job, especially very early on when identity is so tied up into who they were literally days ago. You know, like a week ago. The mobile person, the working person, the money making person, the father, the mother, the whatever.

Finding Meaning in Recovery

And then, you know, you're dealing with a physical crisis, the existential crisis, the identity crisis, like you're dealing with it all in the one moment, and you're trying to get them to sort of see, well, you know, you're still you and how we're gonna move forward with the still you person, like we're still gonna move forward with that person. And then later does come an adjustment of what that you looks like.

did for me like it's a massive adjustment into what me looks like. But my identity wasn't so much tied up in a one label specifically, although, you know, I s I was the person who felt like they needed to be the main breadwinner, you know, that you know ran a business that did all these things. I I had a big strong identity. But

I think one of the things this is going to sound weird or might even sound logical depending on

like who you are and why you're listening to this podcast. But for me, the fact that my brain went offline was a really good thing because it and that allowed my emotional side to come to the fore. Like it really enabled me to see things with a different intelligence, you know, and access part of me that my emotional intelligence perhaps that I hadn't that I perhaps suppressed previously, you know, and just battled through things.

And that kind of allowed my identity to come with me, it allowed me to leave some stuff behind and allowed me to

bring into my identity this emotional side of me, you know, which who cried, who got excited about new and different opportunities, you know, that my head didn't convince me out of. You know, so there was a lot of silver linings that I didn't I wasn't able to iterate back then. I wouldn't have been able to tell you that it was a silver lining. But now and a few years later, after it all happened, I was definitely able to talk about those silver linings. Kylie

Do you you're fourteen months or so out, right? So maybe you're not there yet, I don't know. But are there some silver and I know a hundred percent Nicole was one of those silver linings, I get it. but do you see some silver linings in this whole saga? Yep. I do. my relationship with my daughter got stronger. Yep. So that was all s that was

definitely a silver lining. and you know, I I'm was very grateful before, but it cemented how g how grateful I am for my circle of friends.

Yeah. Kylie's friends were amazing. Yeah. Your friends were amazing. Yeah. Yeah. Yeah. Big family still in Australia is is there a big family in Australia, Kylie? Not not a big one, but my mum and dad are still still alive. So they're they're in Melbourne. and my sister is in on the Gold Coast and my brother is in Melbourne as well. Yeah. And my and my son is in Adelaide.

Okay. So you still have some family here, but then you were able to create a community in the years before the stroke in Bulgaria. Yeah. you you were doing it a little bit tough after the stroke. Yeah. Correct. Yep. So that's spot on. Did you Nicole tag team with some of those people as well? Yeah, so Kylie's friends were

beautiful and they were looking after me too. So

When I was in Bulgaria, they were looking after me, you know, giving me dinner and what have you, and kind of giving me emotional support as well. And I think they were grateful that I was there from a skills point of view, like they were doing a beautiful job of supporting Kylie emotionally. But and I did kind of train them up a little bit in in some rehab as well, you know, how to help with approaching from the right and how to communicate and also just even doing some activities.

Kylie and I had the balloon and we were tapping it back and forward to each other for strengthening up the right arm. And then we'd play some kind of word games as we were doing that for some speech therapy. So I was educating her friends around that kind of stuff. But the other thing, Kylie, that you and I have spoken about is, you know, after the stroke is knowing what's important and how to let some sh shit go that would have been, you know, annoying or you know.

focus on something and now it's just you you just know it's just not important. Yeah. Being able to just let crap go. Correct correct. and the other silver lining is that I got engaged. Yes. Did he propose soon after? Yes, in the in the rehab hospital. what a romantic Yeah. But he but he said that he'd

already decided before the stroke that he wanted to marry be ma be married to me. So he just hadn't got around to asking me yet. Yeah, fair enough. That stroke has a way of interrupting people's plans and the things that they think they're gonna do. so Nicole you normally treat your patients. They get to a stage. Usually they're a lot

better than they were when they first met you. And part of what you do is you send them off into the big wide world like a kid. I've grown you know, I've raised them, you know, like they know how to comb their hair now. And you kinda send them off and it's kind of bittersweet, I imagine, but also a very important part that the people who you're helping get better actually go off into the world on their own.

And stop needing to be supported by you. I know there's some people who need more support and that continues for longer and some people who don't get enough and it and it's never enough. But what's it like knowing the job is not done, but you still have to leave and go home? that was heartache. I mean, Kylie

and I both balled our lies out. it was a long flight home. Yeah. Yeah, it was a long flight home.

with lots of reflections. I suppose the good thing at that point was Kylie was easily able to speak on the phone or message each other. So and also, you know, I think at that stage maybe I got to see the brain scan and I was just like, my god, how have you even survived this? 'Cause I think was it about a seven centimeter bleed, Kylie? Yep. seven and a half.

Yeah. To be precise. It truly felt like a a miracle. And again, full kudos to the surgeons in Bulgaria, truly, for that acute care. Because I think Kylie, I feel like you were in surgery in about within about two hours or something after the stroke, which is phenomenal. And, you know, your friends really saved your life. taking you straight to the hospital and prevented like, you know, more serious outcomes from the stroke. So yeah, so for me,

I was proud of myself as well. and I, you know, I like to live my life by thinking I can look myself in the mirror. And I felt like I can really I've got a tear, really look myself in the mirror. Yeah. Doing the right thing. Yeah. Yeah, yeah. Yeah. You came to the need of somebody who was in need and needed specifically not only your love and support as a friend, but also your skills. Like you had the complete package for them at that time.

How long did you end up staying in total? Was I ra away about just under two weeks probably with the flights and everything like that? So yeah. so yeah, leaving was leaving was horrible. But the goal of being able to go to the toilet was met. and also just the skills for, you know, skilled up a few other people and Kylie, you know, had her good networks.

I also went out to Kylie's property out in the village to have a look at any home modifications. So that was another kind of OT type role that that was done. and she's got an amazing property out there, but it is kind of needs a bit of love and so that was also just reassuring her partner too, like reassuring Guido that no, look, Kylie's got this. There were a few times where it was like, Nicole, I don't want her to do this. Like I'm like Guido, she's safe. She can do it.

She's got sitting balance. She's okay to sit over the side of the bed. She can wiggle sideways. But he was anxious. And so again, part of my job was to reassure him to make sure that he let her do things. and didn't step in too quickly. And so

as an OT, we're all used to like sitting on our hands and taking time and letting people struggle a bit. And it was hard for him to let Kylie struggle. So to just encourage him to let her struggle a bit so that she could do it herself and just wait. Just

take the time, especially with communication. so yeah, I I kind of obviously knew there was a lot more rehab to be done, but I also had seen Kylie's determination and that, you know, she kind of knew what to do. and and so that was I I was grateful again for that. Kylie, what was it like when your friend had to leave? I was heartbroken.

The Impact of Caregiving

I felt like she was a lifeline and I felt like that that had been cut because obviously she speaks English and obviously like

Obviously we have a really good relationship. and I felt like I was in a like how do I describe it? In a in a sea of

not n of people not understanding. So yeah, not my friends, but the hospital staff, basically. So not the not the physios. Like Nicole said, the physios were exceptional. but, you know, just the hospital staff. Yeah, just generally speaking. So did you feel like she had put you on the right path? Were you more confident with

kind of where she left you as opposed to where you guys started and was that enough to kind of give you the foundation for what you needed to take responsibility for when she left? Definitely. yeah, definitely.

Yeah. Man, w what a kind of interesting whole situation. You know, if this was fifty years ago, there's no way anyone's going anywhere to help anyone with anything. you know, like your hospital s experience in country like Bulgaria after what they've been through would have been completely different. You know, your s the chance of surviving telling your story is probably s you know, very much

decreased. I know this is gonna sound weird, but like it's never been a better time to have a stroke in in most of the world. Like let's face it. the the possibilities are just endless. I'm a miracle from all the medical professionals that put all their time and effort in. I am eternally grateful to my occupational therapists and

physios and surgeons and people who invent X ray machines and people who make C T scanners and

The plastic bottles where drips go in, like every single thing is just an absolute miracle of God or medicine or science or I don't care what, like whatever you want to call it. And it just to me, it you know, here's a really terrible situation and here and and but look at all the amazing things that came out of it. Somebody from the other side of the planet to be able to come over and intervene in that way, train people up. Like, man, it's the

Perfect like feel good story, you know. Everything's going okay, things turn shit, and then something good comes out of it and yeah hopefully there's more good to come, you know. Like, man, it's just an amazing experience. I just feel really privileged to be able to hear it and share it further. No, not not not me, personally.

but now that you say that I will s I will think about it now. the most thing that that Nicole and I reflect on is, you know, like like we've already said, how good was that my friends got me to the hospital quickly? How good was the the surgeons the surgeons

because it could have all gone wrong. or gone gone a different way. so that's the stuff we reflect on more. and just just like my amazing recovery.

Reflections on Recovery and Gratitude

Because I recovered so quickly and so well, like I've thrown everyone away here. So so my new my neurologist, my my physios, ever everyone here is like well, back then was like really surprised. So we it's when I first walked into the n neurologist, she said, like, wow,

No one expected you to recover that quickly from such a severe stroke. Yeah. That's such a good outcome. I like to I like to think that those things wouldn't have been possible without your most amazing superhero friend Nicole. Nicole, your final thing I'd like to kind of run by you is that your whole career you're working towards making things better.

Yep. Like for people who are going through all really difficult times. have you had you ever dealt with a family member who needed your intervention or family

friend or someone like that that needed an intervention with your specific skills before this? man. yes. So when I was quite a young therapist, probably in my early twenties, my dad told me that his

One of his like great aunts or cousins elderly relative had had a stroke and she was in hospital and I didn't really know her. Like she wasn't someone in the family that I I had knew had known. And I said to Dad, I'll go and visit her in hospital. And and so I went to the hospital and I found out she was in this room and I walk into the room and there were four people.

And I see this gorgeous little old lady who is all crumpled in her chair and squashed and nearly falling out. And I I just walked in and I was horrified. And I just walked straight over to her. And I just said, look, can I help get you more comfortable, get you into a better position? And then I realized it was it was my own relative. and I said to her, I'm Nicole, I'm John's daughter. you know, dad's asked me to come and see you. And and she just said the most cutest thing ever. She said, when you walked into the room.

You just look so lovely and I hoped you were here to see me, but I I wouldn't have known what I could have done to deserve that or something something dead cute. anyway, she'd had a very dense stroke and they were basically saying that she wasn't a candidate for rehab and that she should go straight to a nursing home. And her daughter was a nurse.

And she said, Nope, Mum's not going to a nursing home and she ended up taking her home and I used to go every night after work and do rehab with her. she ended up being able to walk quite with a pretty awkward gait and a and a stick. but she got back to, yeah, walking and living at home and I just again always think that if she didn't have her daughter, the nurse and myself, she probably would have ended up not not walking. Yeah, being in a nursing home.

It's not that quality of life. So there's people who definitely go through that. And what I love about you sharing that part of the story is there's people listening and they're paying attention and maybe they haven't been given the amount of therapy that they feel they deserve or need. And maybe that's going to trigger people to go, you know what, stuff this, I'm gonna find a way to get more therapy, I'm gonna ask. I'm gonna hassle some people, I'm gonna be a pain in the butt to some people, I'm gonna do more.

for myself to get me further. I love that you shared that part of the story. That's kind of the unique experience that a that a a seasoned occupational therapist can kind of impart on us who are early on in the recovery about like how you need to advocate for somebody or yourself for more physical therapy. And and even if you

Can't access that people listening and watching YouTube channels. Go to YouTube. There are a ton of awesome therapists on YouTube showing people how to do exercises at home. Yeah. And I mean, I just took some really basic things. We s I, you know, stole some things out of Kylie's flat to take in. And Guido's son gave me some toys and we use those like stacking things to, you know, do rehab with Kylie's hand. I took some pegs from her house and we made

an activity of pegging up the curtains to do shoulder and arm rehab. So you can often do a lot without, you know, complex equipment as well. Yeah, brilliant. Well, Kylie, what a friend, huh? Yes. Yeah. As if she wasn't a good enough friend already. Yep. I really appreciate you guys reaching out, joining me on the podcast, sharing the story from

your unique perspectives. it's so good to get that kind of a story and have it told in two perspectives, in one sitting. I wish you both well in your future work and Kylie in your recovery. And I really I I'm very grateful to have been able to have this conversation with you both. I'm just gonna say you're my superhero, Kylie, seriously, the effort and the rehab.

yeah, do not want this about me. yeah, seriously. Thank you. That means a lot,

Bill Gasiamis (1:03:44)

Well, that's it for another episode of the Recovery After Stroke podcast. What stays with me most is how much of Kylie's recovery came down to the people around her. A nineteen year old daughter signing consent forms she never expected to sign, a friend who dropped everything, retrained hospital staff, and fought for something as basic as Kylie's dignity in using the bathroom on her own. If this episode raised questions for you about who's actually positioned to make decisions for you in a crisis,

It might be worth having a conversation with your own family. And if you want to hear another Stroke Survivor story of navigating a stroke far from home, go back and listen to Kristen Taylor's episode Stroke Abroad. If this episode meant something to you, share it with someone who needs to hear it today. And if you

want more on rebuilding identity and finding transformation after the stroke, my book.

The unexpected way that a stroke became the best thing that happened is available at recoveryafterstroke.com/book. If this show has helped you, you can support it at patreon.com/recoveryafterstroke. I'm Bill Gasiamis. Thanks for listening. I'll see you in the next episode nineteen-year-olds.