

# Stroke with Hayette Wilkinson

**Speaker Key:**

**CB** Chantal Boyle

**HW** Hayette Wilkinson

**VO** Voice Over

**VO**

Welcome to The Sunflower Conversations, where we explore the Hidden Disability Sunflower and its role in supporting people with hidden disabilities.

00:00:20

**CB**

Hello, everyone. I'm Chantal. And I want to welcome you to Instagram Live. So these Instagram Lives are part of the Sunflower Conversations, and... Hi, Hayette.

**HW**

Hi, Chantal. How are you?

**CB**

I am very well, thank you, Hayette. How are you?

**HW**

I'm fine, thank you. Has it started?

**CB**

So I'm just explaining to everybody that this is part of the Sunflower Conversations, where we talk to Sunflower wearers about their lived experience with disability. And we are very delighted to welcome you as our... This is our second Instagram Live with an actual human being.

**HW**

Yes.

**CB**

The last one I tried to do, we didn't have any signal.

**HW**

Okay.

**CB**

And we were at Preston North End Football Club, so it was up in the top of the stadium. So it didn't quite pan out as planned, and I had to do a short one on my own. So I'm delighted that we've got the technology to work today.

00:01:20

**HW**

Thank God for technology.

**CB**

Yes, exactly. So I'll introduce you. So Hayette joins us, as I've mentioned. And Hayette experienced a severe stroke, aged 32. So a stroke is a serious, life-threatening medical condition that happens when the blood supply to a part of the brain is cut off. So I'm going to hand the reins...

**HW**

Yes.

**CB**

Over to you a little bit, Hayette, because first of all, I'd like you to tell us, what kind of stroke was it that you had? You have told me, but it's quite a long word.

**HW**

Yes.

**CB**

So I'd like you to say it.

**HW**

So I have my laptop next to me, because I prepared myself, because I like to. So I had two types of strokes, first, subarachnoid haemorrhages. I didn't know what it was. So it's a life-threatening type of stroke caused by bleeding into the space surrounding the brain.

00:02:19

I later learned that patients of the subarachnoid haemorrhaging can die immediately or soon after. And for the patients who do survive, urgent treatment is required to seal off the aneurysms, and there's a very high risk of a second one or often fatal

bleeds. Now, if I was to live and avoid terrible deficits, I would have to have urgent surgery, which is also what happened to actress Emilia Clarke.

**CB**

Okay.

**HW**

Yes. She had a serious stroke as well, I didn't know it before, who is an inspiration for me since she recovered, and so can I. So I can.

**CB**

So you have.

**HW**

Yes. I'm a survivor.

**CB**

Yes. Well, really just from that explanation, I'm really extremely lucky to have you...

**HW**

And the stats...

**CB**

Sitting here right now, talking to us.

**HW**

Yes. And about a third of people who had this type of stroke can die, so I'm very, very lucky to be alive. And a few days later, I had an ischemic stroke. That is the most...

**CB**

So you had the first stroke.

00:03:26

**HW**

Yes.

**CB**

And then you then had a subsequent two more strokes whilst you were in the hospital.

**HW**

Yes. And ischemic stroke is the most common type of strokes. And they happen when a clot blocks the blood flow and oxygen to the brain, which is also what happened to me. Because I have four brain aneurysms, one in the frontal lobe, two on the left middle cerebral and the right middle cerebral. And there were two in the frontal lobe. And they're not big. I just have to be monitored about how they're going on ...

**CB**

So they're still there, those ones?

**HW**

Yes.

**CB**

They're all there. They've not ruptured.

**HW**

Yes. Still there. Just one ruptured. That why it was a bit hard for me, because I was in hospital for eight months. So I had two brain...

**CB**

Yes. So I think a bit hard is a little bit of an understatement as to actually what happened.

**HW**

Yes. So I was, in three months, at King's College Hospital in Denmark Hill. That's where I had my three brain surgeries, one to coil my four brain aneurysms, so they're not... Well, they were sealed off, another one to drain the excess cerebral fluid.

00:04:45

Because after the first one, it was a success, but then my state kept deteriorating, so they had to... The neurosurgeons had to redrill to open my skull so they could remove the cerebral... Slowly, the cerebral fluid, which saved my life as well. And then I went into Lewisham Hospital, that's my nearest hospital, and I was there on transfer for two months.

And then they had a free bed for me at King's College Hospital in Orpington in Kent, South England. And it's where I learned everything, how to eat with cutlery, how to use a pen, walk, even shopping. I needed to learn everything.

**CB**

But did you have any comprehension? When did the first...? When did you first realise that something significant, life-threatening, had happened to you?

**HW**

After, because I rushed into work without knowing. I thought, oh, since all the therapists in the hospital were quite junior, it must have not been a really big, bad, massive stroke. And then, when I went to the brain injury clinic, oh, so I'm not stupid. It's just that I had a serious stroke.

**CB**

Yes. So you mentioned there that you had to... So let's go through. You mentioned about having to learn to use cutlery, etc. What were the physical and cognitive impacts?

00:06:18

**HW**

So physically, on my right, my left, my right limbs are much weaker than the left one. And I'm right-handed, but that's fine. Most importantly, my right ankle and toes are paralysed. And initially, I felt really weak. I couldn't do normal things, like even help carry heavy objects.

It's about... But thanks to physiotherapy, I managed to have a flicker on my small muscles on the right ankle and right toes, but it still doesn't move. But it's about practice, practice. Maybe the first one is hard. The second one is going to be much easier and the third one and so on. So just rehearse, rehearse, rehearse.

And I still struggle with the feelings in my limbs. Sometimes, when I cook, I feel exactly the same. So I got referred because my community therapists discharged me, and I went back to my occupational therapist, because I still need some help holding a pot and pen.

And they said, just don't worry, it's normal. Nobody understands what is subarachnoid haemorrhaging. They give me exercises so I can improve, even like cleaning my flat, I don't know. So they give me tips on how to clean. And my biggest issue is my cognitive impairments, because I just feel stupid all the time.

**CB**

But can you explain why? What was the difference before and after?

**HW**

So before, I was really, really clever. Well, I was quite active and driven. Now I'm still driven, but I don't feel clever at all. Even you tell me a word, I don't even know what that word is. Like my husband, let's go to plant. What do you mean, plant? A plant shop? A plant or a factory? See, I don't know. And I rushed into work without knowing what happened to me. And I was suspended because of my cognition impairments, and I...

00:08:22

**CB**

So was this after the eight months?

**HW**

Yes.

**CB**

This is after eight months rehabilitation. You went to work.

**HW**

One year. One year.

**CB**

One year.

**HW**

Eight months and three months at home with community therapist and seeing physiotherapy, occupational therapy, and what was the third one? Speech and language therapy. Very helpful when you can speak. And at least I got support for a few months, and then... So that was... So September 2021, I had my severe stroke. I was discharged on 31 March, 30 March 2022.

And then, 15 September 2022, one year after, I rushed into work. After, because occupational health don't understand hidden disabilities, including stroke, neurology, it seemed deemed acceptable that I would be fit to work within six to eight weeks. And after seven weeks, I was not coping. Because even watching videos, like onboarding, I didn't understand them, and I thought I as stupid.

00:09:29

**CB**

So it must have been very difficult for you, having to be...

**HW**

Yes, difficult.

**CB**

But you have improved significantly, haven't you, from where you were?

**HW**

Yes.

**CB**

Being able to have this Instagram Live and figuring out how to do it...

**HW**

Yes.

**CB**

You wouldn't have been able to do that before.

**HW**

No. Now, yes.

**CB**

And your energy levels, what are your energy levels like?

**HW**

Much better, because I have strategies, how to manage my fatigue. I love that image, because I'm more visual, I love the battery level, when you start at 60% and 100%. And when you wake up, most people wake up with 100%, and mine is 60%. And each time I do a cognitive task, like cooking or watching a film or video, it depletes the battery. And when I do a lot of cognitive activity, then I just feel so tired that I can't even speak or do anything.

**CB**

I don't think that people generally probably... Well, I think we all take our bodies for granted until something happens. And I don't think, often, that we maybe think that actually how tiring using your brain is.

00:10:42

**HW**

Yes.

**CB**

You think about, well, if you're running here and you're running there and physical activity. But actually, just using your brain is exhausting.

**HW**

Yes, because the brain is the most important muscle, because that's how you use to make decisions, how to plan, how to look after your family. And before, I used to be able to organise everything. I would like to say I was maybe the CEO of the family, planning holidays. Now I can't. Well, it just takes me longer to organise it. I need to plan it ahead, much longer in advance, then I can do it.

**CB**

Yes. So what have the changes been? So if you tell us about your family. You've got a child, husband.

**HW**

Yes.

**CB**

So how old was your child when you had your stroke?

**HW** So our son is called Aiden, a very Irish name. He was a baby when I had my stroke, I think 14 months old, very baby, so tiny, so sweet. And it was tough, because I was separated from him for eight months, eight long months, and only being able to see him at the weekend on a monthly basis. And my husband organised everything for this. He even organised even for my family and friends to come one after the other, because it was during the COVID.

00:12:04

**CB**

Oh, gosh.

**HW**

Yes.

**CB**

Yes, of course.

**HW**

So mask and the... How do you call them? The gown.

**CB** So did everybody have to have masks on?

**HW**

Yes.

**CB**

So you couldn't see their facial expressions.

**HW**

Yes.

**CB**



And what about with your baby? Could you have them up? Could they...?

**HW**

No, [overtalking].

**CB**

You couldn't have the facial... Yes.

**HW**

But you would just see the expression from the eyes, yes.

**CB**

Oh, gosh. That is tough.

**HW**

Yes, very tough.

00:12:31

**CB**

So tough. And tell us about the photos and the pictures of him that...

**HW**

Yes. So my husband and my family put a lot of pictures about us and my family, put it everywhere, in every room where I was. Even in ICU, intensive care unit, they put it everywhere for me to recognise and... Because they knew that something was wrong with my brain, so for me to remember even speaking to... I had a lot of visitors, and sometimes I didn't recognise them. It was tough.

But for my son, so I was in an induced coma for three weeks. And they let me to... So let my small brain to recover from the severe stroke. And when I saw him, I [unclear], is that my son? He looks so different. So it was a shock to me. I was flabbergasted.

**CB**

Yes. Because you probably hadn't realised how much time you'd been in the coma.

**HW**

Yes.

**CB**

I guess you lose time, don't you? You're not conscious.

**HW**

Yes. Unconscious. And when I was discharged from the last hospital, I was so happy. Yes, I'm fine, I can do it. And I went to the nursery to pick up my son, and he was over the moon. He ran, ran, ran, mama, mama. And then I couldn't pick him up, only a few minutes, then my husband took him. And then the very next day, he realised that I wasn't the same mother. He became really cold with me. So it was tough for me.

00:14:06

**CB**

That's heartbreaking.

**HW**

Yes, heartbreaking. It was a shock. And it took us maybe a year to get a relationship, but not like we were before, because you can't compare versus what we had before, but at least it's a little bit better. Now, he doesn't... He cuddles me, he kisses me and do snuggle-snuggles. [Overtalking].

**CB**

I think when we spoke before, you had mentioned that because your face had been affected...

**HW**

Yes.

**CB**

Then you weren't able to give him the facial communication.

**HW**

Yes.

**CB**

Which is so important, which is one of the things with the face masks and COVID which was so detrimental to people's mental health, was because of not being able to pick up on how people were feeling. So when it's your own baby, that... Oh, gosh, I can't imagine.

**HW**

It was tough.

**CB**

You are listening to the Sunflower Conversations with Chantal. To share your story and find out more information, details are in the show notes.

00:15:09

**HW**

And since I was in hospital for eight months, I missed his first steps. But now I can see him running and laughing, so I was, oh. He's my source of inspiration, because if he was able to learn how to walk and eat and dance, I can do it as well.

**CB**

Yes. You're learning together.

**HW**

Yes. We're learning together. But in terms of my speaking voice, so I didn't know it before, I thought I had aphasia, but actually, no. Part of my brain that was damaged was the left temporal lobe, which is important for language. I had a lot of thoughts in my head, but I couldn't get any words coming out of my mouth. And a day when I was in Lewisham Hospital, the one in transfer, I said no to my husband. I don't remember it. He told me. And at least it was progress. I could finally speak.

**CB**

It was your first world, no,.

**HW**

Yes, first word, no. Because he used to do everything for me. I was, no, no, no, but I couldn't say words. And I realised afterwards that I had a mild to moderate communication disorder, with high-level language and cognitive communication issues. Had more difficulty understanding inferences and subtleties in written and spoken languages and following complex conversation. Initially, after more than three people at a time, I couldn't. But now it's better.

00:16:37

**CB**

So you needed people to be completely direct with you.

**HW**

Yes, just...

**CB**

But no fancying up the conversation. Just say exactly what you mean.

**HW**

Yes. But now it's better, because thanks to a lot of speech and language therapy sessions, I can understand. Even in loud areas, I can manage it. It's about being exposed to more... What do you...? How do you call it...? Discomforting environments.

**CB**

Language and conversation.

**HW**

Yes. Discomforting myself enabled me to get better. And that's what I did. And I feel that now, I can manage to have more facial expressions, especially on my right side. Because before, I couldn't even lift it.

**CB**

Oh, really?

**HW**

And now I can. And I tend to make a lot of mistakes in both English and my mother tongue, French. I may struggle with word finding. What is the word for it? How do you call this? Also, I can't translate between the two languages either, but I just laugh about it.

I tend to make mistakes in both masculine and feminine pronouns, like her, his, but I laugh about it, because I should know, because they exist in French. Even simple expressions like the difference between got to, and go for. Now I know what it means, but it took me a long time to understand what it means.

00:18:06

**CB**

Yes. Because I am a native English speaker. I've tried to learn to speak French. My father actually lives in Paris. And trying to get the masculine and the feminine, the words, is very, very difficult for me. But when you've grown up with it, it's just ingrained, isn't it?

**HW**

Yes.

**CB**

So for you having to then be like, I'm not actually sure about this, must have been a very strange sensation for you.

**HW**

Well, French is harder for me to process, well, to speak than English, because I lived in London for 12 years. I had my stroke in England. And I live with a British/Irish man, and I speak mostly English with him. And now it's just easier for me to speak English.

And sometimes when I'm with my family who don't speak one word of English, most of them, I don't understand. I say, what do you mean, [French], because... Yes, but it happens. But thanks to a lot of speech and language therapy, I was able to read a bedtime story to my son, and it's a pleasure.

**CB**

Oh. Yes. Because that's one of the things, isn't it, with children? It's doing that storytelling.

**HW**

Yes.

00:19:26

**CB**

And having that cuddle time.

**HW** Yes.

**CB**

It's really important.

**HW**

I have to impersonate as the characters. So if there's a bear, I will do bear talk. If it's a mouse, it's... I love doing this.

**CB**

Yes. So your relationship with him now is good.

**HW**

Yes.

**CB**

And your husband sounds like he's an absolute dreamboat. He must be exhausted.

**HW**

He's exhausted, but never admits it.

**CB**

Well, it must put such a strain on the relationship, something... What's happened to you is not an everyday thing.

**HW**

No.

**CB**

So he's had to pick up the reins of everything.

**HW**

Yes.

**CB**

And also have the worry about are you going to recover, and how is your recuperation recovery, etc.

00:20:19

**HW**

Yes.

**CB**

So it's a lot.

**HW**

A lot for him, but he doesn't want to admit it.

**CB**

Oh. And then you've done some really amazing things for charity.

**HW**

Yes.

**CB**

For stroke charities. Can you tell us about those?

**HW**

Yes. So Hidden Disabilities. I'm wearing my lanyard, Sunflower lanyard. Because initially, I didn't know what it was. And my amazing community occupational therapist, Emily, if you see me, well done, Emily, because she told me that this is for... This is a sign to say that you have a hidden disability. I didn't know. Initially, I just thought it was... Just employees have it.

And this really important to tell them that, yes, I have a hidden disability. And I love your website that you shared with me, Chantal, where you have all the different types of hidden disabilities. And before, I didn't realise understand some. And now, thanks to your website, I know them, and you have some nice cards and ideas as well. Now, because since I have a brain injury, I have the brain injury ID card, because someone made it for me, with my symptoms.

00:21:34

And I also support Different Strokes, because thanks to them, I did a few challenges. I love a challenge. I did the March On, to walk 5k steps a day for the whole month of March. And I did the abseil off the ArcelorMittal [overtalking].

**CB**

That is the ArcelorMittal Orbit?

**HW**

Yes.

**CB**

Via the Olympic Park?

**HW**

Yes.

**CB**

Well, I've been on that, and that's where you go up and you go down in this sort of bag, like a helter-skelter. But you abseiled down there?

**HW**

Yes, abseiled down. I was scared, but...

**CB**

Very brave.

**HW**

I was very scared, but then I was buzzing. Yes.

**CB**

Good for you.

**HW**

And then I did...

**CB**

With that thing, you've got to get your... I don't know what the word is, but your... Is it...? Your coordination right to do that.

00:22:23

**HW**

Yes.

**CB**

That's a difficult thing to do. So that just shows how far you've improved.

**HW**

Yes. And then afterwards, I did do climbing, another tall building in Canary Wharf in London, to climb 48 floors, 1,031 steps, in 30 minutes as well through my employer, Unilever. And I managed to do it.

**CB**

Well done.

**HW**

And if you are disabled you can do things. It's all about mindset over physical pain, should I say? Yes. And then I'm also in the loophole with the Stroke Association. I have an interview, I think next week, to be a live... What is it called? Live connected support, to be able to speak to other stroke survivors to get them better.

**CB**

Well, you are definitely a source of inspiration. So I'm sure that what you have to say is going to be so valuable to them [overtalking].

**HW**

Absolutely.

**CB**

And have you connected with other stroke survivors? Do you have a network of people that have had a similar experience to you?

**HW**

Not really, because there's lots of different strokes, and I don't think that anyone would have the exact same as one.

00:23:49



**CB**

Yes, okay.

**HW**

But there are...

**CB** Every experience is different.

**HW**

Yes, every... Strokes are different. It's very unique. Because me, my... How do you call it in English? My symptoms are very specific, but might be different for someone else, based on which part of the brain has been impacted. There are some that are much worse than me.

And sometimes, when I see some of them, it's like, oh my God, thank God I'm alive. Thank God I'm not severely disabled. I'm just a work in progress. But seeing people who recovered fully, I'm just impressed [?]. How did you manage to do it? It's pure mindset and push yourself hard, which is what I'm trying to do.

**CB**

Yes. But the reality is that that doesn't necessarily always happen for some people.

**HW**

No. You just have to push yourself, because nobody is going to do it for you. You have to drive yourself.

**CB**

Yes. And so have you had to have, oh, counselling to deal with what's happened to you, like this traumatic journey?

**HW**

Yes. Quite a lot of psychologists. And I think the most important one has been CBT, cognitive behavioural therapy. Had some before, but the one that I had was just brilliant. Gillian Hussein, if you see me, you're amazing. And then also Daria [unclear], you're amazing. And both psychologists in the brain injury clinic.

00:25:23

**CB**

Yes.

**HW**

To help me get better and have strategies and tips regarding my cognitive impairments. Before, I used to think that I was a useless mother. They said, no,

you're an okay mother, you're a good mother. Because every child is so unique, you can't compare, because... Yes.

**CB**

So can you just briefly tell me, cognitive behavioural therapy, what does that consist of? What does it mean? Because there's different types of therapy, aren't there...?

**HW**

Yes, there's lots of different ones.

**CB**

Where CBT is used.

**HW**

Yes. So it's a talking therapy to help manage the problems by changing the way you think and behave. It helped me a lot, because sometimes, yes, like I told you, I just thought I was not good / slash, yes, not...

**CB**

And it's all happened through no fault of your own.

**HW**

Yes.

**CB**

At all.

00:26:21

**HW**

Initially, I thought it was my fault that I had a severe stroke. No, I was just very unlucky. And when I found out that I had a lot of brain aneurysms, four in my brain, it's because I suffer from polycystic kidney disease. That happens quite often, because it's genetic. And then one of them burst because I suffer from hypertension, and a lot of people in my family suffer from it.

**CB**

So it was nothing...

**HW**

But never tell you.

**CB**

That you could have prevented.

**HW**

No. It happens.

**CB**

It happens, and you're here, thank goodness, to live to tell the tale. And you're doing lots to support other survivors and help raise money and share your story. And I think that that's wonderful, that you're doing that and you're trying to help other people who have had a stroke.

**HW**

Yes.

**CB**

And the impact that it can have on the family. And you as an individual are now actually relearning and knowing your worth. So we've got another podcast coming up which will be a little bit more in-depth, for anybody who is listening. And it's going to be with the charity, Different Strokes, and Hayette is also going to join us on that. So we'll have a charity expert.

00:27:40

So if anybody's got any questions that they would like to ask the charity, then please do send them to us. You can send us a DM or you can pop them in the comments, because we'd really like to get your questions answered. It's such a complex disability, and apparently, stroke is the cause of most disabilities or something like that.

**HW**

Yes.

**CB**

I'm not sure of the exact fact. But I wanted to say thank you for your first live. It's our second.

**HW** Yes.

**CB**

And thank you very much. And thank you to everybody who joined.

**HW**

Thank you, everyone, and have a lovely, exciting day.

**CB**

If you are interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner. Thank you for joining the Sunflower Conversations podcast. Remember to hit subscribe.

00:28:37

## **VO**

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