A Night For Aphasia – Olivia O’Hare

Held annually, a night for aphasia is the brainchild of speech pathologist Olivia O’Hare. The event is designed to educate Australia about aphasia.

Socials:
https://www.facebook.com/anightforaphasia/
https://www.instagram.com/anightforaphasia/
https://www.nowweretalkingspeech.com.au/

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Transcription:

Olivia 0:00
I think it’s really important to also acknowledge that it’s not just the client that you’re working with, it’s very much the support network. They’re just as important because they’re obviously going through it all as well. So to be able to assist the client, but also work with a family in an end-user really collaborative approach, I think, yeah, it makes all the difference.

Bill 0:23
How do you equip the family? Are they usually involved in the sessions? Do the sessions all happen in clinic? Or do that happen at home? How does that work?

Olivia 0:31
With the clients that I have, most of them come to the clinic, and it's with their partners. So as much as I can do it in an hour session really the rest of the time, every minute of every day, they're with their carer. So I want essentially, to be able to train them to be a mini-speech pathologists that's specific to the client because they're gonna do most of the work. I'm just teaching them how to do it.

Intro 1:02
This is the recovery after stroke podcast, with Bill Gasiamis, helping you navigate recovery after stroke.

Bill 1:14
Hello, and welcome to recovery after stroke, a podcast full of answers, advice and practical tools for stroke survivors to help you take back your life after a stroke and build a stronger future.

Bill 1:26
I'm your host three times stroke survivor Bill Gasiamis. After my own life was turned upside down, and I went from being an active father to being stuck in hospital. I knew if I wanted to get back to the life I loved before, my recovery was up to me after years of researching and discovering or learned how to heal my brain and rebuild a healthier and happier life than I ever dreamed possible.

Bill 1:51
And now I've made it my mission to empower other stroke survivors like you to recover faster, achieve your goals and take back the freedom you deserve. If you enjoy this episode and want more resources, accessible training and hands on support, check out my recovery after stroke membership community created especially for stroke survivors.

Bill 2:11
This is your clear pathway to transform your symptoms, reduce anxiety and navigate your journey to recovery with confidence, head to recoveryafterstroke.com To find out more after this podcast. But for now, let's dive right into today's episode.

Introduction



Bill 2:28
This is Episode 150. And my guest today is Olivia O'hare, a speech pathologist who is also the founder of the annual event A Night For Aphasia. Olivia O'hare, welcome to the podcast.

Olivia 2:42
Thank you. Thanks for having me.

Bill 2:43
My pleasure. Thank you for doing the work that you do. And I'm gonna let you explain what that is. But you're the kind of you're my favorite kind of person because you guys, like many other people around the planet, you know, and Australia and our communities help out other stroke survivors, you look for ways to support stroke survivors from the different ailments that they have. So tell me a little bit about the kind of work that you do?

A Night For Aphasia



Olivia 3:14
Of course, it's a very nice compliment. Thank you. So we have only just started putting together an awareness campaign called and that for aphasia. And so I suppose there be lots of questions coming through about specifics.

Olivia 3:29
But essentially, it is an event and night that we raise awareness for the condition aphasia and help the wider community as well as allied health professionals, and general public students, whoever wants to come along, learn a little bit more about what aphasia is.

Bill 3:49
So how did you get an interest in that space, though?

Olivia 3:53
Yeah, so it was in my final year of speech pathology. As a student, I was working at a hospital rehabilitation center, and I was given this client on very last minute, which I think is just very, very ironic, fantastic way that it all happened.

Olivia 4:14
And I'm really, really thankful for this last-minute patient that I got, and there was very limited information provided. So it was really a matter of sort of jumping in and getting to know this patient and their partner. And we were going through some initial rapport and trying to get to know each other a little bit better.

Olivia 4:38
And the file that I was reading with the presentation that I was given just something just wasn't brash. So going down the track and sort of doing a little bit

of research and a bit of investigation, we actually discovered that this person does have aphasia and wasn't accurately diagnosed.

Olivia 4:55
And I'm sure you're well aware of the whole element of spontaneous recovery. So that real initial curve where post stroke, you do see some really fantastic gains. And this poor patient wasn't able to have or make those gains because their diagnoses wasn't necessarily accurate.

Olivia 5:17
And it's no fault of any of the doctors or speech pathologists, I think it's purely just to do with the awareness around what aphasia is. So that didn't sit well with me. And that's essentially how ANFA wass born.

Bill 5:30
Wow. You know, you talk about it, it was nobody's fault. And I kind of understand that there's a possibility for people to fall in between cracks. And there's so many reasons why. But did that person have a traumatic brain injury? Do they have a stroke? How did they get to be in front of you?

Olivia 5:51
Yeah, of course. Great, great question. So they did have quite a large stroke. And they've gone through the process of this particular hospital, obviously, in acute care, and then moved to inpatient rehab, and we were then a part of my role was part of ex-patient may have so they'd come in, and we'd work with them.

Olivia 6:14
And they had quite significant impairments. So this particular patient was completely nonverbal, and had a paralysis in his left side. So had already done a lot of work. And I'm not sure I'll kind of explain it, but they, this particular client must be separating a lot.

Olivia 6:37
So a lot of repetition of certain words and sounds that made them they were under the impression that they were producing language and sentences that were making sense, but it was the same, same words, the same sounds being repeated. So really difficult, I suppose in jumping in, obviously, halfway through.

Olivia 6:58

So as a previous qualified speech pathologist, working with them, and sort of coming in as a student with no experience of what aphasia is, and really trying to figure out where they're at and how best you can facilitate their recovery and work with them to make some gains.

Bill 7:15
How old? Were you at the time?

Olivia 7:20
25.

Bill 7:23
And what were you are just like a problem solver. I know how I'm going to fix this, I'm going to help. what's the what's the, the mindset of somebody who's in that role? Because I'm a bit of a problem solver and I go after problems.

Bill 7:38
And I figure if we follow if we go for the solutions and focus on what the solutions are, how we can overcome those problems. And spend more time there, we're more likely to get to some kind of an outcome that's better than where we started. Right? What kind of curious mind did you have?

Olivia 7:55
Yeah, great question. So I'm definitely considered a bit of a problem solver. I think it was also really fortunate, obviously, this patient had been through the system, literally from from day doc to, I think was almost seven months post-stroke from when we met.

Olivia 8:13
So fortunate to sort of have that holistic understanding and to see him at that point. And not so much from where he started along the journey. So I think that definitely helped.

Olivia 8:26
But yeah, it just didn't seem like the facts sort of matched. So fortunately, being a student, all that research is quite in the forefront and yeah, fresh in your mind. So it kind of it just fell into place. Which was really lucky.

Bill 8:45

I had a really interesting experience. I was presenting to the third year occupational therapy students, probably about 2015 I think it was March 2015. And I was presenting about my story, they bring in a real live stroke survivor, and I talk about things that are related to stroke to give the students a understanding of what it's like to experience a stroke and then go through the rehabilitation phase.

Bill 9:12
And then what was done well and what may have been missed, and just to give the students an insight into what a stroke survivor's experience is. It was brilliant for me to be there. And it was really brilliant for them to have me there. Right was great all around.

Bill 9:30
And what was interesting is that out of nowhere, one of the students at the end raises her hand and says, do you have left side numbness or left side what does she say left side temperature difference? Actually something like that.

Bill 9:47
And she was sitting I would say a good 15 rows behind where I was like, in front of me but like 15 rows back and I said to her what makes you say that? She goes, cuz I noticed in the different color of the skin tone on your hands.

Bill 10:09
And I said to her, well, my gosh, that's an amazing thing to notice. Because yes, my left hand is a lot colder than my right hand. So it probably appears more pale, as opposed to the the other hand, and that's because it's always colder.

Bill 10:24
And I'm not sure whether it's blood flow or whatever, but yes, it is. And I attend to her lecture her and this person, you know, deserves top marks. And it was kind of that thing, it was fresh, there must have been something that triggered that for her that was recent.

Olivia 10:47
And I think it's important with aphasia, too. I mean, there's so many different presentations. And I think that's an element of the lack of awareness can be disguised as many other conditions or many other communication disorders. So I think it's a matter of sort of taking that step back and looking at it holistically and

being like, okay, hang on a second. There's, this which would fit into this category, but there's actually X Z that would fit into this. And it was yeah, just sort of putting all the dots together.

Bill 11:16
Yeah. So what are the presentations of aphasia? What are some of the common ones that people miss?

Intro 11:21
If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind. Like, how long will it take to recover? Will I actually recover? What things should I avoid in case I make matters worse?

Intro 11:38
Doctors will explain things, but obviously, you've never had a stroke before, you probably don't know what questions to ask. If this is you, you may be missing out on doing things that could help speed up your recovery.

Intro 11:51
If you're finding yourself in that situation, stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you. It's called the seven questions to ask your doctor about your stroke. These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke.

Intro 12:09
They'll not only help you better understand your condition, they'll help you take a more active role in your recovery, head to the website. Now, recoveryafterstroke.com and download the guide, it's free.

Different Types Of Aphasia – Olivia O'Hare

Olivia 12:24
So there's a lot of different types of aphasia, and it depends on what part of the brain has been affected. And I'm still learning about aphasia, and I'm trying to raise awareness.

Olivia 12:35

So there's still a lot of work that's being done to understand aphasia, and I think, not only understand that, but but to be able to consolidate it to a point where we can teach the general public or teach someone that might not know as much about the anatomy.

Olivia 12:53
I've actually written the different ones down. So there's Anomic Aphasia, which is fluent. So the the output, there's a lot of verbal output, but a lot of those key words are lost. So it's a bit of word finding like oh, can you go get that thing, you know, the thing over there, that's, that's sort of, there's lots of language coming out, but it's not as specific as we might like.

Olivia 13:18
And there's Wernicke's aphasia, which is where the Wernicke's part of the brain, that's obviously where the damage has occurred, which typically presents as low receptive. So the understanding and that comprehension, you can see a bit of an impact there and doesn't mean that intellect isn't intact.

Olivia 13:39
And I think that's the most important thing with aphasia is that all people that have an intellect is intact, it's just their difficulty, to perhaps demonstrate that intellect in whatever way. So there's also mixed in nonfluent aphasia, which can come across as quite effortful speech.

Olivia 13:59
And it's a bit of a mix of Wernicke's and Broca's, which is the next one. Broca's is reduced expressive language. So we call that nonfluent aphasia. So very, very limited output. And this is the presentation that my patient had. And then there's Global, which is the most severe, and that is essentially all of the above in terms of presentation. And that's obviously really, really, life changing really difficult.

Bill 14:30
Yeah, in these levels of aphasia, different types of presentations, is the person able to get a pen and paper and for example, complete the sentence with that missing word there instead of trying to say it would that missing word be there or not?

Olivia 14:48
Depends on the type of aphasia. So, for I think it's, yeah, I'm still getting my head

around it for Wernicke's, and Anomic aphasia, I do believe that there is a greater ability to be able to write expressively use your expressive language through written.

Olivia 15:11
There are also different levels of that written expression. So it might be more like an elementary level that they can sort of get back up to, compared to obviously, where they might have been pre-stroke, or pre-traumatic brain injury.

Bill 15:27
So in stroke recovery, the most overused word is neuroplasticity, in that it has this great has a connotation of like this amazing thing that's gonna happen, you know, I just rewire everything and everything will come back and it'll be fine. And I understand how we got to that point, because a lot of it is definitely possible to rewire.

Bill 15:50
For example, my leg rewired its ability to walk, even though it has motor sensory neuron issues where it doesn't exactly know how to send information to the brain that it's on the ground, just like my other foot is, it sends that information across slightly differently.

Bill 16:06
But nonetheless, that's enough information to have created a new neural pathway helped me walk and appear as if there's nothing wrong with me or my brain or my body.

Bill 16:17
So in aphasia is neuroplasticity something that can be harnessed in that dramatic inability to express can we retrain somebody to learn how to use words again and find ways to make sentences again?

Olivia 16:35
Absolutely, yeah. And whether that in terms of the full extent, so looking at potentially global aphasia, where that's the most severe? And whether there's research or not, if that can be done? My belief is absolutely, there's always a way.

Olivia 16:51
And I think hope is the most powerful out of everything, in terms of

neuroplasticity, but yeah, I do believe that. Yeah, we I mean, we've, we've had many clients that have worked really hard and gotten back to least some sort of functional language from them.

Bill 17:11
So that's controversial, because doctors might say, well, there's no research to back that up. And if there's no research to back that up, you know, there's some anecdotal evidence but what can really go by the anecdotal evidence, and I feel like roof stroke recovery is all about actually about anecdotal evidence, it's actually got nothing to do with the research.

Bill 17:29
Although the research is good to put in a book and to tell somebody you know, with a, with a really massive head, brain situation, you know, where they overthink is and then perhaps very cognitively intelligent, you know, from a book perspective, if you talk to stroke survivors, like I have, of you know, there's probably almost 150 podcast episodes now.

Bill 17:55
The anecdotal evidence seems to be really dramatic, in expressing the possibility that something is possible beyond what the doctors say, cuz believe it or not, many doctors still give the patients the "This is all you can expect." Or we probably shouldn't expect much more from that person right?

Bill 18:18
So when somebody comes to you, and they perhaps have been given the bad news, how do you bring them on board? Because I imagine that part of the therapy actually requires you to recruit that person into having belief and hope, just like you have belief in hope for them. How do you bring them on board when they've had the bad news?

Giving The Right Motivation



Olivia 18:42
Yeah, great question. So I suppose I'll start with talking about there is a bit of research around neuroplasticity and reconnecting or re-innovating neural networks typically takes around 400. This is what research has suggested around 400 repetitions to be able to begin that re-innovation.

Olivia 19:05
But up to 10, with play. So for me, my approach is very much through high motivation, high enjoyment. And I think that really brings it back to starting off by building rapport and making them feel comfortable and just saying, look, this is what we're going to do, like we're going to get there. It's not a matter of if it's a matter of when, let's get going. And let's have fun while we do it, and then the rest just falls into place.

Bill 19:32
Wow. Have you had results where the client was even surprised by what they were able to achieve, say in a couple of sessions, or even, you know, many years down the track. Did you had that type of experience where they've been able to say to you I can't believe I'm talking or?

Olivia 19:51
Yeah, so I actually had a client that has been told by multiple allied health professionals Look, this is probably as good as you're gonna get, which just is heartbreaking to hear and it should never be said even if it might be true, I think there's always hope and hope is the strongest, the most important part of recovery for anybody.

Olivia 20:18
So I have had a client that's walked through the doors, obviously very deflated being told, that yeah, they're not going to get any better. And this is as good as it gets. And with aphasia, obviously, and essentially completely nonverbal. And we've now gotten to the point where they have improved so much very, very slow gains, but gains nonetheless.

Olivia 20:43
So they've got two or three words that they're saying independently, a lot more repetition, in terms of being able to prompt them to get these words out, it's limited now in terms of what I need to do. It's a couple of things here and there.

Olivia 20:57
And you know, they're getting there, and I can see it, we're really, really close. We're on the edge of a big breakthrough with language. So yeah, and I think that's all down to just them enjoying it, and being told that they can do it. Human body is amazing.

Bill 21:11
It is amazing how does it change their life, because I imagine life's normal, have a stroke, life's not normal. There's a lot of emotional challenges associated to not being able to communicate and express yourself and say the things that are important to you, especially with regards to your care.

Bill 21:28
So how have you found your clients respond to that? Like, what do they say about how it's changed the life? And is it the really big things that changes their lifestyle? Or their life? Or is it a little minor things?

Olivia 21:43
Yeah, that's a really good question. There's definitely, I mean, just as a speech pathologist, I think we have the best job in the world. And that is very bias. But we, as humans exist to communicate.

Olivia 21:58
So even if that's in a wave, or a hug, or a smile, and anything that we can do to help an individual who's, you know, fallen so far in terms of their ability to communicate, baby steps, baby steps, it's the same level of celebration and success. And it's just, yeah, it's the best job in the world, I feel really lucky.

Bill 22:22
Yeah, I think it's a really cool job, too, because you're actually giving people back something that they thought perhaps was lost. And they really use to help solidify their identity as a human being in the planet, and how they go about their community and how they go about their family and the roles that they play.

Bill 22:41
So, yeah, it's very important work. And I can see why you get so excited about helping somebody and seeing them move beyond their condition, and then get better.

Family Involvement – Olivia O'Hare

Olivia 22:56
I think it's really important to also acknowledge that it's not just the client that you're working with, it's very much the support network. They're just as important because they're obviously going through it all as well, in equal, if not sometimes greater implications in terms of their life functionally.

Olivia 23:19
So to be able to assist the client, but also work with the family in end-user really collaborative approach, I think, yeah, it makes all the difference.

Bill 23:28
Okay, interesting. And I agree with you, 100%. How do you include the family? Are they usually involved in decisions to decisions all happen in clinic? Or do they happen at home? How does that work?

Olivia 23:39
Yeah. So with the clients that I have, most of them come to the clinic, and it's with their partners. So as much as I can do it in an hour session really the rest of the time, every minute of every day, they're with their carer.

Olivia 23:58
So I want essentially, to be able to train them to be a mini-speech pathologist that's specific to the client, because they're, you know, they're going to do most of the work. I'm just teaching them how to do it.

Olivia 24:09

And so yeah, I think it's really important that families involved just to be able to get, you know, progress and move towards your goals as quickly as you can.

Bill 24:18
Is that a relief for the family members to come there and get some kind of pathway to supporting their loved one in the frustration or in the challenges when the difficulty of not being able to communicate because I coached them, carers of stroke survivors who are struggling with not knowing how to be a carer specific to that person's condition that person's deficits as a result of stroke.

Bill 24:50
Because they've never been involved in a medical setup anywhere, let alone specialize in stroke and they were just a regular person going about their life and now they're a carer. So how do the carers respond when they've been given these tools?

Olivia 25:07
So, so well and so positively and I think, if anything, because obviously, there's so many tools that you can implement, and you want to find something that works for the family, you don't want to just say, hey, do this and then trying to adapt to something that just doesn't work.

Olivia 25:21
So I think, in a lot of the initial sessions, it's really about finding the right tool. And being unbiased individual within that partnership and saying, hey, talking to the client, saying, hey, do you think that this would be useful? You know, tell me yes or no, if they're non verbal, or you know, thumbs up, thumbs down, nod, shake or verbalize yes or No, tell me, do you think that this would be useful?

Olivia 25:45
And they can tell you objectively, yes, this is going to be great or not, I'm not keen. And it doesn't really impact the carer, they can kind of be motivated by yeah, what the clients wanting to do what the carrier can do, and then kind of working on that more collaboratively instead of it just being pushed upon them. So yeah, I think it's a really nice, nice way to show the tools work on it together and then go from there.

Bill 26:14
Is there a lot of frustration and crying and emotions during a therapy session, or

during a session where the clients in a clinic with their family, do you get to see people really sort of in pain or the opposite, really happy with what they've been able to achieve. Is there many expressions that you get to see?

Olivia 26:37
Yeah, yeah, every session. I also, it might just be the relationships that we've created, but I will often get phone calls from carers, just saying, hey, I need a chat. You know, family members might not understand or it's someone that does understand where this particular client might be at.

Olivia 26:58
So certainly a little bit of counseling involved, and just having that really nice relationship. And they're certainly some of the lows. But also, I get texts throughout the week being like he said this, or guess what just happened. So that's always really exciting.

Olivia 27:14
And I love getting those messages. And so a lot of particular therapy approach that we use for aphasia is called melodic intonation therapy. So it's through singing, and fluency. And with these particular clients that we work on, there's always happy tears when they start to sing because, it just comes out.

Olivia 27:36
And, you know, obviously, they're great songs with a kiss and eagles and Elvis, so it's, you know, just fun as it is. But those emotions that they they feel just to be able to express in whatever way is Yeah, pretty incredible.

Bill 27:52
Can you tell me, this is a multimillion-dollar question. Can you tell me why is it possible for people to sing? And why is it not possible for them to just speak? This is amazing and brilliant.

Bill 28:05
And you see it in Alzheimer's patients who are not physical and then they hear a lovely song, and they get up to the dance floor and they dance around like they used to 30 40 50 years ago?

Bill 28:16
What happens there? Is there a different pathway that gets activated? How does

that work? And then the follow up question is how do we bridge that experience into talking?

Procedural Memory

Olivia 28:28
Yeah, great question. So and a lot of that is to do with procedural memory. So people with aphasia, will be able to tell you the days of the week, Monday, Tuesday, Wednesday, counting, happy birthday, it's all things that we sort of have learnt and repeated so much over time that it's just there.

Olivia 28:49
And so you'll find with songs as well, for these particular clients that we work with. There's the melody to sort of carry it through, but also they're obviously familiar songs. So they've got that long, long, long term memory.

Olivia 29:05
Obviously, we wonder how that would translate when it's words like yes, no, and mine and yours and drink those particular things. But for example, when we sing Happy Birthday, that procedure comes through. And it doesn't necessarily need a context it's there.

Olivia 29:23
But with yes or no and words we're starting to receive, we've got the word but we're applying it to a context there's a few more levels in terms of how we use that language and semantically, how it's related to the context and the situation.

Olivia 29:39
So to answer your question of how to put them together, that's kind of how melodic intonation therapy was introduced. So it's using rhythm, but in speech, so that's sort of an approach that we're using but I think, repetition as well is going to be a big difference.

Bill 30:00
So getting them to sing a song that has the word Yes. In their or knowing there. Is that helping with the inability to say yes or no, individually or separately when they're just speaking? Is that how you kind of train it?

Olivia 30:20

Not necessarily. Because again, it has to be to do with the semantics of the conversation. But it would be something like how are you, or banana. So you're kind of carrying those syllables across.

Olivia 30:41
And you'd find that you'd practice that phrase, and then you'd ask the question, what's the yellow that monkeys eat, and then they'd be able to go banana, which is just insane. I just still don't fully understand how it works. But it does work, which isn't that easy.

Bill 30:56
I know that there's a lot more. I'm not sure what the word is study, feedback research, there's a lot more information together on the field. And I know that it's pretty difficult to answer my questions just like that in a really short amount of time. But I appreciate you trying.

Bill 31:14
You're a little bit like me, you tend to get sucked in, right? So somebody sends you an SMS and you think, Oh, my God, like, my day is done. I've achieved amazing things. I feel really great about that, because somebody gave you feedback. And that's what happened to me with the podcast.

Bill 31:31
It was never meant to be 150 episodes, you know, I never had any real plans for it. But then somebody on the other side of the planet says, I really enjoyed that episode. Thank you so much.

Bill 31:40
That's just like me, I can't believe that I found your podcast and then I'm like, Well, I don't want to do it anymore those days, you know, it drives me nuts. And I'm frustrated, and I'm tired, and I'm having my own stroke recovery issues.

Bill 31:53
And I say ah, but that person sent me an SMS so far, you know, that's not the reason to stop my problems. Not the reason to stop, I should keep going. Because there's people around the planet.

Olivia 32:06
Making a difference.

Bill 32:07
Yeah, that want to hear the next episode. And it does make a difference to them. And therefore it makes a difference to me. And the cycle continues that I can't jump out of the loop right? Do you relate to that?

Olivia 32:19
I do. Yes. Definitely. in many different ways, obviously, with ANFA being one of them. But even with clients, it's more similar in the sense that I can't say no, if it can help someone. So I have my own private practice.

Olivia 32:42
And I get calls, obviously, we've got a bit of a waiting list as much most speech pathologists do. But any client that calls and they're two or younger, and they have a language delay, I just can't say no, just because it's that peak developmental times I'm like, Oh, okay, yeah, add them in, somehow I'll figure out how to help whether it's just doing a free consult with parents to educate them on how to do it.

Olivia 33:07
Or, yes, I'm pretty hopeless in that sense, as well, if you can help. I mean, why not? You've got the skill. Or in your case, you've got the experience and that really unique perspective and the skill to be able to run a podcast, so you can't stop.

Bill 33:22
Yeah, I love it. So let's talk about A Night For Aphasia. So not only can you not stop, you also needed to take it to the next level, right? So you've got a speech pathology, practice, you help people that you can't really fit in. And then one day, you decided to create a evening to celebrate raise awareness I imagine to raise funds. Tell me a little bit about why you started A Night For Aphasia.

Starting A Night For Aphasia



Olivia 33:53
Yeah, fantastic. So we had our first event in 2019. And that was the same year that I've met this client. So we actually pulled the event together in about six weeks, which was just awesome. And I think, yeah, it was perfect timing, because we had, we were kind of striking while the iron was hot and had some really great responses from peers and larger organizations.

Olivia 34:19
So we were lucky to be sponsored by the brain foundation and scope Australia. And they really helped us get things together quickly. And we had 120 guests 10 for the first one. And Professor Miranda Rose, who specializes in aphasia research was able to speak so she gave a really unique perspective.

Olivia 34:19
And we had a fabulous or a couple of fabulous guest speakers, one who was a person with aphasia, and she just brought the house down. her speech was just so unique and pure, and it was the perspective that everybody needed to hear. And I honestly think that she's the one that started the questions of when's the next event? What's going to happen next sort of thing.

Olivia 35:06
So we're really, really lucky to be able to do it again, obviously, not last year, because of COVID. But we've got an event which I believe you're coming to, exciting, in July end of July this year. So essentially, the mission of the event is to raise awareness, if we can teach one person in the room, what aphasia looks like, or how they can interact with someone with aphasia to make their life easier in the community.

Olivia 35:38
We've succeeded, we are really fortunate to start we're now starting to get a lot of guests that have aphasia come along, and the ones that are comfortable are going to have a name tag and say I have aphasia. Please come and chat come and learn about it from the ones that know the best.

Olivia 35:56
So yeah, it's gonna be a really, really fantastic evening, we've got a panel of guest speakers. So we have a speech pathologist who's jumping on a person with aphasia, and a carer of a person with aphasia. So through really unique perspectives, and some food and drinks flowing and some great raffles and giveaways. So, yeah, it'll be really, really great night.

Bill 36:23
Sounds like I am really looking forward to it. I would love some tips on how to actually interact with people with aphasia, though, because although I've had a stroke, and although I went through, not aphasia, but some real cognitive, serious cognitive issues at one point.

Bill 36:39
I've never experienced aphasia, especially anything long term that impacted my ability to communicate. And I found myself fumbling and stumbling across those conversations. And I've found myself saying some things that come from a really naive place about people with aphasia, and it's not my fault, it's just that I've got no clue.

Bill 37:06
So if somebody comes across somebody with aphasia, or if a family member might be listening to this, who has recently had somebody who's now experiencing aphasia, what are some of the tips that you could give them and me about how to be sensitive? I'm not sure if that's the word to that person who has aphasia?

How To Interact With People With Aphasia

Olivia 37:31
Yeah, absolutely. And so the things that I've learned from my experience so far, and I'm still learning, I think the most important thing is to take your time when you're speaking, speak slowly. Be patient is definitely something that I've learned

from many, many reports of people with aphasia over time is that it might take them a bit of time to put their message together, or work out what they need to say.

Olivia 37:59
So embrace those awkward silences and just wait, wait for them to say what they'd like to say. I think it's really important to remember that their intellect is intact. So they might appear differently, or they might sound differently, but you certainly don't need to dumb down your language to be able to interact with them.

Olivia 38:21
And yeah, just speak slowly and you know, be patient. It is difficult because of the different types of aphasia, there are different presentations or different difficulties that they might have. But yeah, just be mindful and patient and wait.

Bill 38:45
Yeah, sometimes it's a little bit difficult for people to wait because there's some information that you want, and you haven't got time, and you want it now, and who knows what I don't know what goes on.

Bill 38:55
But I think most people would sort of stumble across it unless I'm speaking from my own experience from just the bad habit of perhaps telling, you know, one of the kids in it, spit it out, or telling, you know, whomever friend of mine, you know, like, what do you want to be? I don't know what you're talking about.

Bill 39:15
I just find myself going back to those old habits of talking to people who are quite capable of talking but perhaps, you know, distracted or stuck in the conversation or whatever.

Bill 39:26
And us just sort of saying, you know, tongue in cheek and spit it out, tell us and that sort of tends to be the place that I might go to and be insensitive as a result of that to somebody with aphasia.

Bill 39:43
Have you found does aphasia get in the way of people going back to employment

and being fully able to return to work? Say their other deficits have been sorted out or overcome? What does it stop people from doing?

Olivia 40:02
There's definitely a functional impact. And so I mean, the patients that I'm working with, do have quite limited output in terms of their functionality in society and in the community.

Olivia 40:18
But having said that, like Emilia Clarke from Game of Thrones, had an aneurysm and had aphasia, and then has fully recovered and finished off the Game of Thrones Season, so you can fully recover.

Olivia 40:34
And yeah, she's obviously back to it, and a lot of people with aphasia have, had it and worked hard and recovered fortunately, quite quickly, a lot of it within the spontaneous recovery, but then some, it might take years to recover.

Olivia 40:49
And some might not ever get fully back to where they were previously. And depending on the symptoms, and that level of severity, there's certainly the possibility of them not being able to go back to work or participate how they'd like to in the community, which is really upsetting.

Bill 41:10
Now, I suppose it's interesting way to go about motivating oneself about whether or not you're going to do work in this space or not, it's like trying to give people the opportunity to give back to something that perhaps was lost and, you know, would bring them a lot of joy, just talking would bring people a lot of joy.

Bill 41:34
But then that other level of you know, it stops people from being fully active member of the community or their family is difficult, do people does the general public and I'm generalizing, and I'm not trying to pick on anybody, but the general public, make it harder for people with aphasia.

Bill 41:58
Now, I'll tell you why. And I know that in Melbourne, where we both live, I believe, we've got one of the best city designs in the world. So if you've got a

wheelchair, you can skate down a ramp.

Bill 42:11
When you're crossing the road and get up on another ramp when you want to get on a bus, there's a ramp to get on the bus when you want to get on a train or a tram, the wheelchair just rolls in, and it's all perfectly fine.

Invisible Disability

Bill 42:22
So there's a lot of awareness about physical disability that's visible. But is there a lack of awareness about for lack of a better term, invisible disability, and how we support people that are experiencing things like communication issues?

Olivia 42:44
Yeah, absolutely. And I think people are very quick to judge. And this is obviously again, a generalization, but a lot of people are often quick to judge and, and don't give the time that that person with aphasia might need. Often that judgment just comes from them, being unsure of their own safety.

Olivia 43:09
But you can imagine the impact that would have on a person with aphasia, who might be in a therapy session trying to practice their community engagement. So that might be a therapy session out at Bourke Street. And I might be trying to initiate a conversation by saying hello.

Olivia 43:24
You can imagine the mental health implications for someone trying to do that when a member of the public would just be scared and walk away or say I wouldn't do it and get out of here. So yes, certainly, I think, because it is invisible. It is really, really difficult.

Olivia 43:46
And you don't want to go down the path of putting labels on lanyards or ways to sort of label or identify yourself differently. So it's a really tricky balance. And it's something where I think ANFA hopefully will fill that gap a little bit, just helping create awareness.

Olivia 44:05

I mean, aphasia is more common than cerebral palsy, Parkinson's, and multiple sclerosis combined. And I can, I mean, I know, I knew about all three of those things before knowing about aphasia, and it's just the awareness. It's just the awareness, I think, will make a really big difference.

Bill 44:25
That's stunning. What you just said, that is stunning, because I've heard of all of those things. And I didn't know what aphasia was until I had a stroke. And aphasia was a word that was being used a lot in stroke communities.

Bill 44:40
It seems like people who have aphasia, missing the one thing that allows them to be advocates for themselves, they're missing the ability to communicate. And therefore, if you can't communicate your challenge, you can't make anyone pay attention and take notice, especially at the political level and at the level where perhaps, where you can ask for funding for example.

Bill 45:05
I know that stroke suffers the same thing. It's strokes the leading cause of disability yet we hear about all of the fundraisers for cancer, cancer research, whether it's breast cancer, prostate cancer, you know, any type of cancer, you name it. In Australia, we do awareness about cancer, like no other person, no country on the planet.

Bill 45:28
But when it comes to stroke awareness, I feel like even the Stroke Foundation struggles to you to utilize the the resources that are available to all these other I'm not sure, you know, ailments. And then when you have a failure, it could have happened because you're a stroke.

Bill 45:51
And that's another level removed. From the difficulty that stroke people face, you have now aphasia people who often come from a stroke background, and then they can't even speak and be their own advocates, I can at least be my own advocate and advocate for stroke survivors.

Bill 46:10
But I don't know how to advocate for aphasia. People who experienced aphasia, I don't know how to do because I'm not in that space. I haven't been there. So I

find it really disheartening, I suppose. But nonetheless, I'm still doing this part. I'm doing what I can in the way that I can.

Bill 46:32
And I love supporting people like you, because you're being the voice for these people. Do you feel like you're the voice? Is that how you would explain it? Or express yourself? Or was there another way to explain or express that better?

Olivia 46:48
I hope that I'm getting across aphasia and the impact that it has on these people and their families. I think it's more just advocacy, really, just really trying to advocate for these clients that might not be able to do it themselves, but also supporting the ones that can and providing them a platform to be able to really get the word out there. And I think, yeah, it's just, it's so prevalent.

Olivia 47:18
And it just needs the light shine on it. So our logo is a spotlight. And I think, yeah, hopefully, the, the amount of a night for aphasias, for all that we can do, the more people we can get on board and, and just raise that awareness. But it is really difficult. And I think, because it is invisible, and it is it presents in so many different ways.

Olivia 47:42
And these different ways very similar to other presentations. It's really hard to sort of quantify or, yeah, it's hard to help people understand what it what it looks like. So we're working on on how we can make that happen. But yeah, advocating as much as we can, in whatever way we can is really important and the same as what you're doing. It's just fantastic.

Bill 48:06
Yeah, is somebody typing in the background?

Olivia 48:08
It's my dogs.

Bill 48:10
That's all right.

Olivia 48:11

There pitter-patter feet.

A Night For Aphasia 2021



Bill 48:13
That's all right. Okay. No problem. So as we get to the end, and wrap this up. Tell me about the event. And is tickets still available? Is it sold out? What's the situation?

Olivia 48:29
Yeah, of course. So the event has now been moved, thanks to COVID to the 30th of July. So we're in our event month, and it's at high ground in Melbourne, which is just a stunning venue just in its own record, but it'll be a really lovely evening at seven o'clock until 11.

Olivia 48:53
Ticket's at $65 and it includes free hour drinks and food package, as well as obviously access to see our amazing panel speakers. And we've got some awesome raffle and silent auction items and all of the proceeds will go towards making the event bigger, and getting more people involved for the next event.

Olivia 49:17
We've also got the Australian Aphasia Association and Aphasia Victoria putting in silent auction item and whatever that sells for they get the full proceeds. So it means that they can get a bit of a boost into their organizations as well which is really lovely. And yeah, tickets can be purchased via our Instagram or our Facebook page. There's a link to try booking on those.

Bill 49:46
What are the Instagram and Facebook page?

Olivia 49:49
Yes, so both called A Night For Aphasia.

Bill 49:52
That's it just look it up on Instagram and look it up on Facebook. Well, I am really thankful that you doing the work How you doing. So I appreciate you for that. also appreciate you coming on to the podcast, sharing your story helping me become a little bit smarter about aphasia and understanding more about aphasia.

Bill 50:10
I love the work that you're doing for stroke survivors advocating for them and all the work that you do. And I imagine all the other people not only stroke survivors who have had, who have aphasia, who came from a different background so thank you for that.

Bill 50:23
And I look forward to meeting you. I can't wait for the night I've seen the venue. And I think it looks stunning, you've chosen very, very well. And as far as the $65 cover charge, I'm a one drink wonder. So if it helps, I'm only gonna have one drink. So hopefully the money that I don't spend on drinking goes to the community.

Olivia 50:46
Thank you, oh, gosh, I think I'll be in the same boat, as you know, but thank you so much for having me seriously, really, really special to you, you're a pretty amazing human and the things that you're doing awesome, I need to go back and listen to more podcasts. I think I was doing a few. Over the weekend. And you've had some really fascinating guest speakers. And I'm feeling really lucky to be a part of that now.

Bill 51:12
You know what I had, which was really amazing. I had, I actually had people with aphasia on there. And some of the conversations were just so heartfelt because one of the guys was 19. And he came on board. I reached out to him, I didn't obviously don't know that people have aphasia when I reach out to them.

Bill 51:33
And he just said yes, straight away. And then I think he said by the way, I have aphasia. So is that, okay? And I'm like, Well, how else are we going to get you on if there's no other way to get you on. So they're really short episodes of the conversation is really, you know, short and succinct so that we can just get general questions, but it's not really about what they're going to share or can or can't share.

Bill 51:55
It's about just getting the man to speak right? I found that really, really amazing. Because I did try to get on some aphasia I'm going to call them aphasia warriors. And a few people at the beginning 2, 3, 4 in a row said, Look, I have aphasia, I can't do it, you know, I'm not going to do it.

Bill 52:18
And I didn't completely understand what that meant when they said they can't I imagine there's a little bit of anxiety, perhaps that they feel due to the fact that they can't speak and they are going to go on a podcast, and it's going to go out to maybe hundreds of 1000s of people.

Bill 52:37
I don't know what right. So I don't push the thing. I don't push the why or the why not. I just love to have people on and if they can't make it, then it's perfectly fine. But when I get people on who have aphasia, and we go through talking to them, I just, it is next level amazing, because it's the hardest thing that they are trying to overcome.

Bill 53:02
So Jack was on episode 127, and the episode's labeled Living With Aphasia After Stroke. And, you know, he was, I think 15 years old when he had a stroke and now has aphasia. And now he's trying to overcome that. And he's doing some great things. And he's going back to school, and it's starting to get back to that part of him his life that he had to put on hold when he was 15 and experience a stroke.

Bill 53:31
So that was really great. And then I also interviewed. Yeah, so the other person was Duncan Campling and he was a stroke survivor, locked-in syndrome, hasn't been able to express himself properly, for quite a quite a long time. And what we

did was we pre-prepared the questions, and I sent it to him, and he responded during the episode with the answers that he had pre recorded via his computerized voice.

Bill 54:02
And he's a bit of a English gentleman from his origins. And as a result of that he had a bit of an English accent to his voice. So we had a really good conversation about you know, 15 or so questions and he responded to them in a way that was really useful. And we just edited that.

Bill 54:23
So it's a really great episode for people to listen to, to just get an understanding of how some other people that are experiencing aphasia or difficulties communicating are getting along and they're not leaving any stone unturned. They're really are taking every opportunity they can to practice.

Bill 54:41
So, just a little bit of inspiration there. Hopefully that people will, hopefully people will resonate with that. Olivia, thank you so much for being on the podcast. I really appreciate it and I look forward to catching up with you in a couple of weeks.

Olivia 54:54
Pleasure me too we'll cheers with a beer. Friday the 30th.

Bill 55:00
Done, thanks so much for joining me on today's recovery after stroke podcast. Do you ever wish there was just one place to go for resources, advice and support in your stroke recovery? Whether you've been navigating your journey for weeks, months or years, I know firsthand how difficult it can be to get the answers you need.

Bill 55:19
The road is both physically and mentally challenging from reclaiming your independence to getting back to work to rebuilding your confidence and more. The symptoms don't follow a rulebook and as soon as you leave the hospital, you no longer have medical professionals on tap.

Bill 55:34

And I know for me, it felt as if I was teaching myself a new language from scratch with no native speaker in sight. If this sounds like you, I'm here to tell you that you're not alone.

Bill 55:44
And there is a better way to navigate your recovery and rebuild a fulfilling life that you love. I've been creating an inclusive, supportive and accessible membership community called recovery after stroke. This is an all in one support and resource program and is designed to help you take your health into your own hands.

Bill 56:06
This is your guidebook through every step in your journey from reducing fatigue, to strengthening brain health to overcoming anxiety and more. To find out more and to join the community. Just head to recoveryafterstroke.com See you next time.

Intro 56:21
Importantly, we present many podcasts designed to give you an insight and understanding into the experiences of other individuals opinions and treatment protocols discussed during any podcast are the individual's own experience and we do not necessarily share the same opinion nor do we recommend any treatment protocol discussed.

Intro 56:38
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Intro 56:55
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Intro 57:16

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Intro 57:40
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