Aphasia Help After Stroke - Tracey Bode

Tracy Bode is a clinical Speech Pathologist who found her passion in Alternative and Augmentative Communication to provide Aphasia Help for patients after stroke.

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Intro 0:02

This is recovery after stroke with Bill Gasiamis helping you go from where you are to where you'd rather be.

Bill Gasiamis 0:09

Tracy, welcome to the program. Thank you so much for taking the time to have a chat with me.

Tracey Bode 0:15

You're most welcome. Looking forward to it.

Bill Gasiamis 0:19

The reason I got in touch with you is that you know, part of what I like to do is put out good information, stories, and experiences about stroke. I got into that because I had, you know, my own experience with stroke, you know, three brain hemorrhages and brain surgery and rehabilitation and I struggled with most of the things that stroke patients relate to and say that they suffer from but on a

very minor scale. And the really interesting thing about that for me is that I experienced a stroke in a form that is mild compared to others, although it's been very challenging, I often found myself wondering what it was going to be like for other people who are doing it a lot harder and a lot tougher. So that was the background for why I began this sharing journey of mine, it helps me heal, etc.

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And one of the most important things to me though was that I was able to talk and communicate my stroke experience and my sharing occurred through talking interviews and all that type of stuff and what I never had I never had a loss in my ability to communicate by voice and it's something that I reflect on and I'm grateful that I didn't have but I know that other people suffer and when the early on in the process I'm concerned that they might be doing it a little bit harder than they need to be, in that they're very over anxious. or over-concerned about what they've lost. And what I want to share is the other side of the story, which is, you know, with work, we can get things back. So that is why I reached out to you. So thank you so much for, you know, giving me the opportunity to share this part of your story. Can you tell me just a little bit about what it is that you do?

Tracy helps people with Aphasia



Tracey Bode 2:21

Yes, it is such a frustrating thing when communication is affected. And I guess that's really what my career is dedicated to helping people with communication difficulties. So communication difficulties can be caused by a whole range of problems like stroke, and some people are born with other neurological issues

like cerebral palsy, which affects speech too, but what these all have in common is they are originating from the brain and the central nervous system.

So what I or what speech pathologists do in general is usually come in after the event at various points and offer therapy or treatment program rehabilitation and alternative strategies as well. So that communication is assisted and facilitated as much as possible because we know it's such a frustration for people when communication is affected, and it can impact so many different parts of your lives studying right down you know, with personal relationships right through to being able to read a prescription on a on a tablet bottle or sign your name. So communication can affect the whole whole range of aspects of your life and the real aim is to try and assist people to have functional communication and then improve their communication skills.

Bill Gasiamis 4:05

Yeah, you know what's interesting? When I read your bio, I took a couple of words out of the bio that really sort of struck me and one of them was communication disability, and I never considered it just I don't know why a disability that somebody can't communicate, but I kind of get help you could be right?

Tracey Bode 4:29

Absolutely. It's an interesting term and it's not one I use commonly. In fact, I was at a professional event and somebody said that they didn't work in the area of communication disability, and I hadn't thought about using that term either, but it does, it covers a broad range of, you know, ways that communication can be impacted and it is, it can certainly be depending on the severity, you know, varying levels of disability, the impact on your day to day life.

Bill Gasiamis 5:07

Yeah, one of the previous episodes of the podcast is a lady called Clodah Dunlop. And she experienced locked-in syndrome after her experience with stroke and yeah, pretty heavy stuff. And one of the things that she had to get back was her ability to speak and now only now today and since that episode, I've just placed the pieces together about how it could be a disability for her because she was in a position where she was fully aware, completely coherent and able to move any part of a body except blink and actually couldn't also speak to say I'm too hot, etc.

And that really just to me is one of those things where while you don't really

realize what you've got to till it's gone but also, how much of a disability speaking or not being able to speak is because she already had all the other disabilities will she also had the inability to communicate and say I'm too hot or too cold or I need something or etc So I love that there are people like you doing the kind of work that we're going to talk about it you do

Tracey Bode 6:21

Yes will in fact that scenario is exactly up my alley because I have really specialized down through a number of you know, there's the common-wide area of communication difficulties and then something more profound and right down to the disability area. And somebody like the lady you just mentioned, who has communication difficulty but also a physical disability as well and that's exactly the area I work in right now, which is with Assistive Technology and alternative and augmentative communication strategies. But that's really really compensatory technique and very useful because it means people can have functional communication restored again or in some different alternative format. There are a lot of other variations in between. So that's kind of the extreme end, I suppose. But it is great to know there's certainly a lot of great technology around to help people who only can maybe blink their eyes, but a lot of other people have, as you were saying, in your own case, a very, you know, more mild impact from the stroke.

Bill Gasiamis 7:42

Yeah. Let's talk a little bit about alternative augmentative communication. What is it? Can you describe it for us and give us a couple of examples?

Tracey bode 7:50

Exactly. So, so the acronym is AAC, alternative, and augmented to communication and I know we always tend to get into jargon but it actually it's kind of meaningful. So alternative communication or augmentative communication. So alternative means an alternative way of communicating. So mostly we use our daily life, speech, body language, and some gesture for our day-to-day face-to-face communication.

If we're looking at an alternative form of communication, we might be well we probably all use maybe writing sometimes that we might type in the email. They are alternative forms of communication, but there are also some alternative forms of communication such as pointing to letters on a leaderboard or using a communication device where you can type out your message and it speaks out for you so they really alternative forms of communication.

You might have difficulty after a stroke actually spelling. And so a letter board might be too complex. And you might prefer to have photographs or pictographs some kind of symbols to point to, instead of having to worry about trying to spell a word that might be just too tricky for you at that time. So we can have symbol boards, and really, they need to be designed according to the persons, you know, where they're at with their recovery and then just whatever it is functional for them, then the augmentative side of it, so what happens is, people, don't generally lose all of their skills.

So you might have a little bit of speech or you might still be able to use your gesture and point to things so we might augment those residual skills following something like a stroke so you might have a bit of gesture and so it might be a strategy to teach some more formal signs or a bigger range of gestures so we augmenting some skills that you already have. So that would be an example of why we say alternative and augmentative because often people do have some skills that we can build on and very few people have, you know, need only an alternative form of communication. Often we can have a whole combination of that strategy, the whole tool kit,

Bill Gasiamis 10:39

Yeah, awesome. Well, I'm curious to give I'm curious to know how to give some guidance to people who might be listening and whose family members are going through this now how do we, what needs to happen to access this type of support tools, for example, is it something automatically? Or how do we start the process of trying to get out and get our loved ones these alternative methods of communication?

Tracey Bode 11:11

Yeah, that's a great question. Because it is it is sometimes a bit of a specialist field and not everybody that is the clinical team that you're working with, may not always be aware of all the options. So yeah, families might want to explore them themselves. So I guess there are two different pathways that what might happen after a stroke, you might have your therapy and you might be using picture resources and different exercises and that's your sort of therapy pathway where

you're practicing something and trying to improve the skills that have been affected and then the other pathway is having a way to communicate all the time using the skills that you have right now.

And that's where we like to come in with alternative and augmentative communication strategies. And that's why I like it very much. And what was what drew me to the field because it's so practical and you're really looking at the person right now you've walked in the door, what skills do you have? And how can we maximize those skills and give you some tools and strategies that you can use right now today so you can continue to communicate so at the extreme level of being affected by the stroke the lady you mentioned who could be basically locked in and could only blink your eyes well, she can blink her eyes so we can find a way for her to control device a company user that involves blinking her eyes to make a switch to activate a switch and to make a selection of a letter or a symbol or a word.

So that would be at that level whatever skill she's she has we would start there if it's a family member at home and often you know with not such extreme impact of the stroke maybe the person is depends really what type of communication problem they have because there are several different ways communication can be impacted. I don't know if you've been through this before on any of your other podcasts with the types of communication problems which are aphasia, have you haven't done that?

Bill Gasiamis 13:53

So tell us a little bit about those. I know Yeah, a bit about aphasia and it's one of the more commonly spoken-about challenges. So tell us a bit about it.

What is Aphasia?



Tracey Bode 14:04

Yeah. So basically because when you've got a had a stroke, the brain is being affected. So various aspects of the brain functioning going to be impacted. And for communication, there are really three main ways communication can be impacted. So aphasia is like central language processing, something's gone a bit wrong with the pathways for central processing of the language so that means people can't say the words they want to say they can't find the words often or they get really stuck. They, because it's coming from the central language processing can't find the words that they want.

They might have very little language at all with very little verbal expression because of that. It also affects understanding so they can't process the words that are coming in. They cannot necessarily understand varying complexities. They might be able to understand simple phrases and sentences, but not the really complex things. It can be a whole range in between and then that also affects reading and writing. Because obviously, when you're reading and writing, you're processing that language in your head to start with, and then you've got to transfer it to the written word or you're reading so that's the sort of Central language processing you're, you're smiling. Does that ring a bell for you somehow?

Bill Gasiamis 15:41

Yeah, I'm glad that you realize that it rings a bell and I wasn't laughing at people's difficult, sitting after the second episode that I experienced. There was quite a lot of information that was missed that was lost, including the ability to speak hear communicate, and type an email, I vaguely recall sitting to type an email, which was going to be a couple of lines. And it should only take moments to

take, you know, half a day.

Tracey Bode 16:13

Yeah.

Bill Gasiamis 16:14

And yeah, half a day. The whole process is not happening. It's kind of like, okay, what's the next word? I want to choose by the time I remember the word, I'd forgotten what I wanted to say.

Tracey Bode 16:27

There you go, exactly the processing becomes very tricky. So it's interesting, you've experienced that and it becomes quite an effort full, I imagine

Bill Gasiamis 16:38

Yeah, and really draining a lot of energy and very difficult to get the brain to do the next thing that you wanted to do because that it's completely, you're completely exhausted at a brain you know level, and the reason why and I only experienced that for a few months and then by the time in a good time to have my neuro-psych assessment, you know, had improved because the swelling had decreased, and all the things that needed to happen started to happen, right? And then it just came online automatically. But I realized that a lot of people won't understand that as healing occurs, things come back. So practice also supports those things that can be a little better.

Bill Gasiamis 17:28

Now, I know that so some of the challenges that occur for speech are created by what we've already discussed, but is it true and is it correct that other people experience speech loss because of being incubated for quite a period of time where they've had tubes in their throat for quite a while?

Tracey Bode 17:51

Yes, and that can happen and I must say that not that would be more of an acute scenario and it's probably not a great, something I've had a great deal of experience there with. But I am aware that that can happen. There's so there are some other things too. So that aphasia is, so what you're talking about is more like a voice, voice weakness, maybe

Bill Gasiamis 18:21

Vocal cord issues maybe.

Tracey Bode 18:23

And yeah, that can happen as well, not necessarily just because of the incubation. So aphasia is sort of the central language processing, causing a breakdown in retrieving words, and understanding and expressing words. And then there are other things that can happen with so this dysarthria, which is a different type of problem.

So this is where people might end up not being able to speak very clearly at all and be very, might have, like, a real slurring of their speech, and they can't make the sounds very clearly and their articulation is really, you know, they really struggle to make the sounds because the pathways the neural pathways to the muscles have been affected. So, whereas they used to, you know, be able to go phew, and put their lips together and make a clear close the sound, they can't do that anymore. Because the pathways are being affected, I know exactly what they want to say.

So they haven't got that central language processing issue going on, it's just now they can't make the words I want to say, which can be even, you know, extra frustrating, then this dyspraxia which is a different kind of nerve processing issue, again, where there's a coordination problem. So the actual muscles around the mouth of the tongue, and so on might work, okay, but the message is being sent down to them mean, that they can't coordinate correctly.

So there's, there are a few different ways the nervous system is affected by a stroke, depending on where the injury occurs in the brain. And then some people might have a little bit of each, or combinations of each of those. So when we look at definitely, there are different types of therapy to help. And that would be different according to which is predominant in those kinds of problems.

Introducing Alternative Augmentative Communication to help with Aphasia



But in terms of introducing an AAC method, that will vary as well, because if somebody doesn't have so much of the aphasia, so they actually know what they want to say, and maybe their spelling skills are all quite preserved, they may be able to quite quickly use alternative strategies and be able to by write spell alternative, you know, as an alternative to their speech. The tricky thing there is the stroke happens on the left side of the brain.

So often people end up having right-sided hemiplegia and if your right hand is dominant, sometimes that can be really difficult to write legibly that you might sometimes people might be able to, you know, use an iPad or a touch screen or something. And there are some very simple there is quite a range of apps, actually, that are in the AAC category. So that's kind of a nice alternative and an option for people, it's a bit of an inconvenience, you've got to carry around a device, and sometimes they might have speech output, but it might not be loud enough when you're at the supermarket or something where there is background noise.

But it's kind of a very socially acceptable thing. This is something that changed in our field with the iPad, that everybody's got one kind of thing. And it's quite an acceptable thing. Even if you have very good fine motor and very good vision, you might be able to say, use a smartphone on one of these apps on it as well. And I have seen people just using even just like the text messaging, or the note section on their phone, that that's really what alternative and augmentative communication is and that would be using something that's fairly mainstream consumer device. But if you can't spell because you do have aphasia impacting, and maybe a lot of people do have difficulties spelling, they might even lose their spelling skills altogether with a stroke. So then you might have a similar thing, but it might have the pictures or symbols to project, you know, just to the single word or that would be one of the ways to use an alternative device.

Bill Gasiamis 23:04

That's excellent to know. So how about assessment? How does somebody get assessed? Because if they wake up, and then they can't speak? Well, you guys have got a tough job, how do you work out whether it's aphasia, dyspraxia, or whatever? Like, how do you do that?

Tracey Bode 23:25

And there are tests, so that would be definitely the speech pathologist's role to put, to carry out those kinds of assessments. And so there might be tests to see what you can understand. And that would start maybe at a word level, can you understand single words? Can you understand short phrases, you know, put the cup on the table, or, you know, just simple phrases? So, you know, that's got a few parts to it. And that's a bit more complex, than just a single word, and then right through to a sentence level. So seeing what people can actually understand would be one test, and then seeing how, like there is a test of naming things, you know, like, how, how is your word retrieval, your word finding?

Can you name things, can you explain things, pictures, and tell me what's happening in the picture, what's your expressive language like, and then that can go right through to a fairly complex level because sometimes somebody might be able to do all of those things very well, that it might be just a very nuanced thing like sarcastic jokes, or some of those more complex, fairly high-level kind of comprehension, there might only be a something some kind of impacted that level.

So the tests can go right through to that level to see if has there been some impact and how severe is it, and at what level are at, so that would be the speech pathologist's role. And definitely, to get all of that understanding of expression, understanding reading and writing voice might be affected, as you were mentioning with people who intubated, that voice might also be affected, just because, again, of the neural pathways, and so some people might have no voice left or just a very quiet whisper, some people might have swallowing that's affected as well. And a speech pathologist would deal with the following issues as well.

So all of those things would come into the assessment. And that's very much, that will be pretty standard for assessment for therapy. What may or may not happen, depending on that point is whether people as the patient at that particular point

are introduced to alternative and augmentative communication methods. So you mentioned a bit about the timeline for recovery. And sometimes it can be a lot of recovery in the first few months.

So you might start off on the pathway towards some AAC method, and then next week, you might not need it, because you've improved sufficiently. So sometimes AAC methods, you know, might be introduced quite early, and it might be just, whatever, whatever is spontaneous, you know, somebody is pointing and using a lot of gesture, well, we will, go with that, or if somebody is really liking benefiting from looking at family photographs, or pictures and needing a cue to help prompt them or they will go with it.

So it's not really like a formal system at that point, It's more what works at the time, And then as time goes on, often once the so recovery can happen for a really long time, up to years but we always want to be making sure we're maximizing the communication strategies at every point. So it might become clearer as time goes on. Actually, it would be really useful to have a communication board or some kind of alternative, a picture dictionary or something.

And it might just be used as a repair strategy. It might not be, you know, this is where the augmentative comes in. It might not be that you need it all the time. It might be just oh right now, this time, I'm a bit stressed out trying to get this message out. And I can't think of the word that I want. So I need my picture dictionary. So I'll have a look and or I'm trying to say this word, and I'm not being understood. So now I'll go and find my picture dictionary or my or try and write, this word or gesture it as a repeat strategy.

Bill Gasiamis 28:14

Yeah, that's what's really fascinating. I was curious, I just picked up there and some of the terminology that you've used you. We've spoken about speech therapists and speech pathologists. What's the difference between one and the other?

Tracey Bode 28:31

Yeah, good point. There isn't any difference. It's really just a change in terminology over the years. So in the UK, they still call actually, they say Speech Language therapist, in Australia we were speech therapists many years ago, then

it changed to speech pathologist. In Queensland, they say, speech-language pathologist, I think there's just I think we have a bit of an identity crisis. Because I think there was a thing about people thinking of speech pathologists. speech therapist is like, elocution teachers or something, you know, this sort of thing.

Bill Gasiamis 29:12

finishing school type.

Tracey Bode 29:14

Yeah, a bit of that. And so, that was kind of a lot of discussion about or what is an appropriate term that really encapsulates what we do, and it still doesn't really encapsulate it very well, because speech pathologists do deal with swallowing issues. And in terms of the area that I work in alternative and augmentative communication. So often people will ring up and talk about, you know, how do we get hold of this equipment?

And how do we find out about it? And, we say, well, you work with your speech pathologist to find the most appropriate equipment and they often the reaction is yes, but the person can't talk. And so why would they need a speech pathologist? So yeah, it's hard to find the right something a communication pathologist might be a better term, but then that term has been pretty much hijacked now by the whole technology industry. And we talk about communication, you know, so much more broadly now, that, you know, with the Internet, and so on, is all about communication now, so that it's the same, the same meaning, really?

Bill Gasiamis 30:30

Yeah, fair enough. How do we go about getting family members to calm down to be okay, and to be able to allow, you know, their loved ones to go through the process? Basically, what I'm saying is, a lot of my challenge when I was recovering from stroke was actually managing everyone else.

Tracey Bode 30:49

Yep.

Bill Gasiamis 30:50

So I was quiet, I was three years in before I needed to actually learn how to walk again, because it was a surgery that caused my deficits, that a long-lasting, so it was kind of like, I was very ready for whatever came because I figured that learning how to walk again, was going to be better than having bleeds in the

brain every so often.

Tracey Bode 31:15

Yeah,

Bill Gasiamis 31:16

So I was very comfortable with having the surgery and then recovering from whatever it was that I had to deal with afterward. But my family wasn't so comfortable with my head being opened up, and all those things happening, how do we have this discussion with the loved ones? Are people going through speech therapy so that we can give the person recovering the space they need to heal or to recover their speech?

Tracey Bode 31:43

Absolutely. It's a great question. And I was just in preparation for our session, I was just brushing up on some of the others, just having a look at some of the recent all the latest research and see, so I've got a review here from March 2018, to just say, what the latest research was showing. And one of the therapy strategies was partner, communication partner therapy, basically. So that is really something that we've probably always done in this field is recognize if you're giving somebody a communication board, this is at one level, the person who you're talking to has to understand it's going to take quite a long time for you to point out the letter and, and get the message together that you're wanting to express. And then given the time and the space to take your time, the time that you need to get that message out.

And the way to achieve that is by training the communication partners that what is required to use these alternative and augmentative innovative strategies. But it's bigger than that, it's exactly as you described, you probably need everybody to be on board right from the start. And so I think that one of the other strategies that in the research that they said was quite beneficial was counseling. And it could be relationship counseling, it might be counseling the whole family.

Stroke can affect so many aspects of life



So it might be something that's done by the speech pathologist. But it might be something more broad-based because having a stroke might affect much more than your communication, the person may no longer be able to work, and they might have a different role in the family. So communication is one element of all of that. But exactly what you said, is so important that everybody else is probably panicking, because maybe they thought you were going to be no longer with them, and they're relieved that you're still alive. But now, you're not the person that you will be before, and how long they're going to take to get better. And are you going to get better at what you know, there are a lot of unknowns for people. And yeah, I can see what you say about your thinking, calm down, everybody, it's an I've got this support, I'm doing my best here.

And I suppose it's a lot of education for people to really understand this whole process. In fact, a friend of mine had a stroke recently, and she was amazingly, recovered fully within a couple of weeks. And I was talking to her about it, and she kept saying, I'm, I'm really so tired. And, and I said to her, so you've had this huge insult to your brain, and you're probably going to be tired for a really long time.

And she said Nobody had mentioned that to her, you know, so sometimes it's just the simple things that maybe, or maybe if she did, it was mentioned she hadn't processed at the time, you know, maybe you need to hear these things a few times, and maybe the family members might need to hear them a few times too if everybody's in a bit of a state of shock, or having a difficult time in the beginning. You might, it might be necessary for the clinical team, or the counselors or whoever, to go through this with people a few times, and I don't know these days with whether in rehab this, the opportunities are there, I know, things have really tightened up with timings.

Bill Gasiamis 35:49

There are two things, you actually nailed it there is that I was told things, and the

photo was never told. So it was really good when there was somebody around to be able to reiterate what was said, and to say, Oh, you know, we get we spoke about that. This is what they said, This is what you need to remember or this is what I've remembered so that you don't have to, etc. So there was that. And then there's also the very big gap between what happens when you're in hospital. And what happens when you go home,

Tracey Bode 36:21

Right.

Bill Gasiamis 36:21

And the biggest challenge for me, I found was in the hospital, they have other priorities, their priorities are to get you healed to be well enough to go home.

Tracey Bode 36:31

Yeah,

Bill Gasiamis 36:32

in the very broad, sort of, you know, expectation

Tracey Bode 36:36

Physical health.

Bill Gasiamis 36:37

Yeah, yeah. So that, so they achieved that really, really well. And then you go home, and you have your outpatient appointments, and my outpatient appointments were 1, 2, 3, 4 a week, for months, and just getting to them and remembering when they were remembering what you have to do there, which one you're at now, and what you're supposed to do it is difficult for most people, and then it's even harder for when you're going through the stroke.

And then at the same time, you get there and as soon as you get there, it's kind of like, right, let's get in, we've got an hour, this is your window, this is how much we have to do. And we want to give you as much as we can, and then you're out and you're going and you're going home. So it's a very whirlwind when the kind of scenario and environment and that and that's why the gap exists. Because we need things explained many times when we need constant effort and support and, you know, tasks, you know, to help us recover, etc, all the time. But we don't get it.

Bill Gasiamis 37:40

And in that time, if we haven't had somebody who is, for example, recording our speech from the beginning to show us what it was like, you know, three months earlier, when we've gone down the path. Often you forget, like how far you've come. So I never had, you know, the foresight to tell somebody to record the way I was walking at the beginning and how I walked at the end, or how I talked and etc. But if there are some people who are listening, a good way to comfort the people who are going through the stroke and trying to gain there, you know, recovery and to get this speech back is to record them speaking and to show them, this is how far you've come.

Bill Gasiamis 38:25

Now, that also helps the person who is caring for that person, because they actually get to say that there has been progress, even though it's frustrating, we're actually a lot further along than we used to. And the only person who really taught me how far along I come was my psychologist who used to sue once a month.

Tracey Bode 38:43

Hmm, interesting.

Bill Gasiamis 38:45

And she would say, well, you're actually putting sentences together. Now, she would say you've come a long way. And we're communicating we're having a different conversation than last time. And that was really heartening to be able to hear her actually notice the difference that was kind of like, Oh, wow, all right, somebody actually noticed the people on there all day, every day, they don't notice.

Benefits of support groups



Tracey Bode 39:07

Yeah, it's I think this is where some of the support group and the external group of family members and other people is, it's probably helpful to have those sorts of supports, and I can't say I know too much about them. But I know when I used to work in a hospital, we would have a stroke group of stroke survivors who come together. And sometimes it was a big social there may have been, a bit of a therapy activity as well, or therapy, and then a cup of tea together or something. So yeah, that's probably another avenue for getting that type of support. Yeah, so in terms of getting the assessment, or the evaluation for your AAC, it might be, it should be the conversation started with your primary speech pathologist,

What we do find sometimes is that people might come back two or three or five years post-stroke and say, now I'm ready to look at an AAC strategy. And for whatever reason, you know, sometimes they might say, I wasn't offered this before. But it might be the same thing that you said, you might it might have been offered that you are hearing it or you were, there were so many other things going on, you weren't aware of the importance of it, or really, what are they even was. So it's interesting that people do come back at various times. And you may even, you know, five years post-stroke, if you still got some residual problems, you may not have a primary speech pathologist anymore, and you might need to start that relationship again. And there are community-based speech pathologists.

There is speech pathology, Australia is the peak body for speech pathologists, and there's a find a speech pathologist part on the website of Speech Pathology Australia. So if you didn't have a relationship with a speech pathologist, then you'd probably use one of those avenues to find somebody if you were still having some kind of annual reviews or something like that with your hospital or rehab center, you could ask them to say, you know, I'd really like to look at some alternative communication strategies, now, you know, what do I do? Where do I

go? Yeah,

Bill Gasiamis 41:56

Well, it's been really informative. Tell me, I know that you're doing a little bit of work with a partner in the UK or in Scotland. Is that right?

Tracey Bode 42:03

Oh, yes. Talking Mats? Is that what you're thinking of?

Bill Gasiamis 42:07

Yeah. Tell me a little bit about that.

Tracey Bode 42:09

Yeah, talking mats is really relevant for people who had a stroke. So talking about, yes. So we are the Australian partners of talking mats and talking mats is a strategy for having a conversation. It's a way of structuring a conversation. So it's not, particularly for people who've had a stroke, it can be used actually, with anybody.

It was originally designed for people with disabilities. So it's designed to make communication easier. But it's also designed to make difficult communication situations easier. So for example, in my team, we actually use it for our staff reviews. So you don't have to have a communication problem to use it. But if you do, it's a great strategy. So it is just a mat and picture cards, and then there's a structure around the conversation. And the idea is to really give them, so the two people having the conversation, the thinker and the listener. So the thinker is the person with maybe the person who's had a stroke. So it really does give them a chance, a good chance to think about the topic and express themselves through this framework.

And the other person, we used to call, the other person, the interviewer, but that was changed. And we now call them the listener. Because of the role, our goal is to be a facilitator and really just ask the structured, use the structure, which involves open-ended questions, so that the person really has a lot of time and space to express their own view about the topic. So it can be, the topics can be almost anything, but you start with a question. So it might be how, how are you going with this at home now? So that might be a self-help topic. So it might be how's it going with your dressing, dressing yourself?

How's it going with cleaning your teeth, how's it going with talking on the phone, whatever, you know, that might be the topic? And so the person really gets a lot of opportunity to think about very specific points. And what people say when they go through this framework is often that they've never had, they hadn't had the chance to think about those things in such detail before. And nobody ever thought sorry, the dogs going off. Nobody's ever thought to ask them those questions before you've got the visual prompts, which really helps keep you on track and gives you just the visual to focus.

Yeah, it's a great framework and a great strategy. So it does we, it's ideal if people can do the training to learn how to implement it. It's one of those things I guess it's like, you know, driving a car water skiing and all those things, I look really easy, and you think, oh, anybody can do that. But does that actually have a lot of strategy behind it, and is evidence-based, which is what appeals to a lot of the clinicians who use it, who like to use evidence-based strategies? So the research in all the categories and stroke is one of them, shows that people get, and produce more information and better quality information using this framework.

And so one of the examples of how it might be used like that self-help idea, you could actually do the talking with the person who's had the stroke and also with a family member, they could get a comparison. So you can say, yeah, I'm doing okay, with cleaning my teeth. I'm doing okay, with, you know, I'm not doing so well with getting up the stairs or whatever the things are, and then you do the same mat with a family member. And then you can say, actually, we need to discuss a few things here. Because, you know, I thought you were doing okay with that. But maybe you need help, and it opens up the discussion.

Bill Gasiamis 46:27

It sounds like a really gentle way to have some maybe hard conversations.

Tracey Bode 46:34

That is such a good point. I haven't heard it put that way before. But that is exactly what it is. Yeah,

Bill Gasiamis 46:41

that's what we really need.

Tracey Bode 46:43

Yeah, that's a great way of putting it.

Bill Gasiamis 46:47

So what we'll do is we'll share with the listeners where they can find more information about yourself and the, and mat, is there a website that we can send people to come and have a look to find more? Find out more about you.

Tracey Bode 47:07

Yes, well, I should declare that, you know, I do run the business that sells, augmentative communication devices, and also we run the talking mats in Australia, but we've very much had a clinical model. And we do even though I'm a speech pathologist, and in my team, we have speech pathologists and occupational therapists, we always work with the primary speech pathologist and the ultimate goal is to always find the ideal strategy for the person, there's absolutely no benefit to us or anybody for the person to have the wrong piece of equipment or the wrong strategy. So yeah, we still have our code of ethics in our ethics that go with us. So talking mats Australia is the talking about website and talkingmats.com is the UK size which has a lot of the published articles and background information so, either of those good links to the talking mats.

Tracey Bode 48:18

The assistive technology that my company zyteq.com.au in Melbourne, and in most states, there are other there are assistive Technology Services, which are sort of more general community-based services. So the independent living centers in most states, I'll see the independent living centers would have a technology department. And the one in Melbourne is called Comtech, so, yeah, there is kind of a network of resources. And again, probably people can look those up and get a lot of information on their own.

But it's still good to get your speech pathologist and or occupational therapist on board as well, mainly too because they can be funding available if you need a device or a tool for your communication. And they will know how to help get the funding organized. And usually, you do need a clinical report to say this is the appropriate device for the person. So there's a bit of a process of evaluation and trialing the device and then writing the report so that everybody's happy that it's the right thing. But if it's an iPad out f the box and you can use it, well, then go for your life, you know, that might be all you need. And then down the track, you might not even need that.

Bill Gasiamis 49:54

Yeah, it's perfect. I love that you have the patient's best interest at heart, I get it. I know I'm glad that you mentioned that you have a business and then it sells these products, etc. I know we didn't declare anything at the beginning. But that's okay. Actually, I want people to come on to the program who are able to offer a solution, even though it's a solution that has to be paid for, funded, or whatever, that's perfectly fine. Because I can't help people if they come to me, I don't know how to help them. I can give them solutions and those types of things. I can only connect them with people who can help and that's what we're what we're doing.

So it's very cool that you mentioned where you're at. And just while we're declaring things and mentioning things, I'm not getting anything out of you or you're not getting anything out of me other than we're having a chat and we're just sharing, there's no commercial deal or anything like that the program is downloaded all over the planet. So there is a possibility for people to be listening in and going, where do we go if we're in the US or the UK or wherever. So, I know that you mentioned there was a.com, so was it talkingmats.com?

Tracey Bode 51:11

That's right. And that's to the talking mats, for the AAC Isaac is the International Society of Alternative and augmentative communication so that international, and that's the peak body, Yep, that has representation all around the world. And there are Isaac chapters in many countries like they're based out of Canada, but there would be a US chapter and a UK chapter. and India and a whole range of other countries would have chapters as well.

And they also would have members from all around the world. So that might be a good starting point to say, Well, I am based in India, what's going on in India for AAC and there are things going on all around the world. So yeah, it's definitely a worldwide thing it does tend it's not only English speaking, there's certainly a lot of European activity and Scandinavian activity around AAC and South Africa.

Some countries might not have as many resources. But you know, you can always make an alphabet board on the back of a Wheaties packet, you know, that you don't have to have fancy tools sometimes. And we do have a really nice relationship with Vietnam among some of the speech pathologists setting up the training school there. So these things are developing all around the world.

Bill Gasiamis 52:48

Yeah, awesome. So that's it, we do have plenty of ways that people can get supported. Hopefully, they understand a little bit better about what, you know, challenges people face after a stroke. With regards to speech, hopefully, some carers are listening. And as a result of that, they can feel a little bit more relaxed and calm about a situation that seems very difficult right now, and, you know, probably is, and hopefully we've been able to connect them with somewhere to go and get some information that they can then pass on to their own speech pathologist and speech therapist so that they can begin a conversation and hopefully that we've created a few ideas about how people can begin the journey to recovering their communication.

Tracey Bode 53:33

Absolutely, no, I think you're spot on there. It is a journey and it can take some time. And there are a lot of resources and strategies out there. So it's just a matter of sometimes getting in in the loop and finding the system and finding where the resources are. So yeah, definitely to reach out to those organizations and just say, put me in touch with somebody in my area.

Bill Gasiamis 53:59

Well Tracy, thank you so much for your time. I really appreciate you giving me an hour of your time and coming on to the podcast. And hopefully, you got a lot out of it. And we can, you know, support you just by sharing the message that you're interested in sharing just through this podcast. And, you know, I love the work that you're doing, you know, we really, truly appreciate it.

Tracey Bode 54:20

Oh, thank you so much, Bill. It's really nice when people benefit from the strategies in the equipment as well. And you can see people's lives changing because communication is so important to every aspect of our lives. So thank you for having me on and giving me the opportunity to share what I know.

Outro 54:43

Discover how to support your recovery after a stroke. Go to recoveryafterstroke.com.