

8 Of The Best Stroke Recovery Tips - OT Sisters

Learn 8 of the best stroke recovery tips as shared by the OT Sisters, Jaimee Perea, and Suzy Burns who between them have more than 20 years of experience helping people recovering from a stroke and other neurological conditions.

Socials: www.instagram.com/o.t.sisters/

Episode 87. Occupational Therapy and Stroke Lecture - Bill Gasiamis

Highlights:

00:53 Introduction
03:13 Suzy's background
03:50 Jamie's background
08:42 Stroke recovery tips from OT Sisters
11:13 Be Intentional
14:44 See The Possibility In Things
16:46 Set Goals
23:39 Repeat Repeat Repeat
32:52 Build Your Team
36:47 Educate Yourself
42:01 Be Your Advocate
46:54 Be Well

Transcription:

Jaimee Perea 0:00

I heard a quote one time and I thought it resonated but I may not get this one hundred percent on but they had said, would you be friends with somebody who talks to you the same way that you talk to yourself? And I thought that was super powerful. You know, just be nice.

Jaimee Perea 0:18

Make friendships with yourself, you know, and it's easy for anybody to focus on the negative and, just be kind to yourself. It's okay if you work hard one day and

the next day, all you want to do is take a nap all day. That's okay.

Intro 0:40

This is the recovery after stroke podcast with Bill Gasiamis helping you navigate recovery after stroke.

Introduction



Bill 0:53

Bill from recoveryafterstroke.com This is Episode 111 and my guests today are Susie and Jamie The OT Sisters. Between them, they have more than 20 years of supporting people with neurological challenges relating to stroke. In our chat, we will discuss their list of 8 tips stroke survivors can use to help during recovery.

Bill 1:14

These 8 tips are not complex at all, and they sure don't cost any extra, but they can make a profound difference to the way recovery occurs. Now if you're feeling a little disconnected from your support team during restrictions and COVID-19, shutdowns, and you're looking for more support, you may want to consider my recovery after the stroke coaching program.

Bill 1:36

People who have already signed up for recovery after stroke coaching get 12 months of unlimited access to a private one-on-one coaching thread with me by a private forum thread inside the coaching area. You have instant access to online training materials that can only be accessed by coaching clients.

Bill 1:56

You get access to courses, monthly training, and challenges made up by stroke survivors, me for stroke survivors. You also get expert interviews that are only available to coaching clients and mp3 you can download them for listening on the go, or training is transcribed to PDF.

Bill 2:14

For people that prefer to read and take notes or highlight important bits for reviewing at a later time. You also get two live hour-long coaching calls per month where you can ask me questions and get answers. You can access the site 24 hours a day, seven days a week, and complete training at your own pace and without needing to leave the comfort of your own home.

Bill 2:36

To find out more about recovery after stroke coaching with me, Bill Gasiamis go to recoveryafterstroke.com/coaching and now it's on with the show. Okay, the OT Sisters, Susie and Jamie, welcome to the podcast.

The OT Sisters 2:53

Thank you. Hello. Thanks for having us.

Bill 2:56

Thank you so much for being here. I am excited because you guys are fairly early in this Ot Sisters game I feel. Tell me a little bit about each of you, whoever wants to go first and go first.

Suzy's background



Suzy Burns 3:13

So I am Susie. I have been an occupational therapist since 2012. I started in home health care and rehabilitation and decided to go on and get a Ph.D. in occupational therapy as well. I specialize in stroke and brain injury rehabilitation now. And then I do a lot of research in stroke recovery, specifically looking at cognition and thinking skills and then ways to use mobile technology to improve everyday life.

Jamie's background



Jaimee Perea 3:50

And I'm Jamie I have been OT for about five years, and I work at a neuro clinic. So I purely work with people who have had acquired brain injuries and I specialize in brain injury as well. But I like vision and so I specialize in vision after brain

injuries specifically, specifically after brain injury and more recently I have an interest in a concussion for getting a lot of I think with the most recent trends and you know, everybody's seeing new stuff with concussion lately and all the new research we're starting to see more clients come in with concussion so that's where I am.

Bill 4:33

Are you guys real sisters?

The OT Sisters 4:35

Yeah.

Bill 4:37

Thank god cuz you look so like. I would have been doing the whole you guys need to have a look into that if you're not real sisters because something is going on there that you're not aware of. I love that people become so passionate about helping other people and then specializing in these fields of stroke and neuro-rehabilitation and all that kind of thing, what drives somebody to become an OT or somebody that helps another person overcome a brain injury Suzy tells me?

Suzy Burns 5:13

I think a lot of people who go into occupational therapy have been touched personally. And maybe they know somebody who survived a stroke. My grandfather specifically had several strokes, they were, "mild strokes" that aren't so mild. And, I think that influenced me to reach out and try to help people going through similar things as he did. So, I think a lot of people are drawn by themselves, those experiences that they have.

Bill 5:47

Jamie, is that your experience too? Is that what motivated you?

Jaimee Perea 5:52

Same man. The same grandpa had gotten in a car accident quite a while ago. It was probably 15, or 20 years ago, and he had a severe injury to his hands. So they had to surgically reattach his fingers. And I thought I wanted to be a hand therapist. And so when I was in school, I did one of my internships in the hand therapy clinic. And then I did my second internship at the clinic where I currently work.

Jaimee Perea 6:17

And I quickly found interest in stroke and brain injury. I didn't know I liked vision at the time, I thought it was going to be like hands-on like a hands-on kind of interest, but it just emerged and I fell in love with the population and seeing people who worked so incredibly hard and then tying that like, you know, like Suzy was saying to some of my family and their personal experiences, it drew me in quick and I fell in love with it and I stuck around.

Bill 6:47

Yeah, that's interesting. That's a great way to get involved. Because there's an underlying emotional reason. And I think if you're going to be an occupational therapist or any kind of therapist, there needs to be the underlying emotional issue and I'm not just talking about the one where you feel sorry for somebody that has experienced something, and now they're unwell, I'm not talking about that.

Bill 7:09

I'm talking about that connection to having lived the experience of somebody that you know, or yourself. Now, I hate saying that because obviously, I don't want any of my therapists to have ever gone through a stroke. But if there is one that makes a really good occupational therapist, do you know what I mean? Because they have that next level of understanding and I hate it for them to become a great occupational therapist in that way.

Bill 7:43

But it does help and I find that when I'm talking to people about stroke, on the podcast, they take me more seriously because they know that I have had a stroke and I can relate to them. And I'm not making stories up and I'm not misrepresenting it, and so on. So I love where you guys have come from is your granddad now taking credit for making these two amazing ladies who have studied this field and are doing great things?

Jaimee Perea 8:17

Unfortunately, he passed away, um, a few years ago, but we know, he's proud of us. And we know he's looking down and, really excited to see where we're at. We talked about it and I wish that I knew before some of the stuff that I knew now. Like he had vision changes, he had changes to his shoulder to motor function, and I wish I could have helped more then I just didn't have education. I didn't know.

Stroke recovery tips from OT Sisters

Bill 8:42

Yeah. So today, we want to discuss a little bit about some of the tips that you guys can share that will help stroke survivors. I think stroke survivors need all the help they can get. Do you guys have some tips that you can share that we can talk about?

Jaimee Perea 9:01

Yeah, we came up with a list of 8 tips to support recovery and recovery means something different to everybody. And we were talking about that before this podcast. So recovery, to one person might be completely different. Someone else you had a good example of that.

Jaimee Perea 9:19

I work with a gentleman in the clinic, and he was a janitor, and he lost arm function completely. He regained a majority of it however, it wasn't perfect by any means. It was functional. There's an assessment that I do with some people called the motor activity log and you rate how well you use your hand on a scale of zero to five and how often you use your hand on a scale of zero to five.

Jaimee Perea 9:44

And so this man he raised himself a 5 out of 5, all the way down the list and, you know, just looking at it from an outsider perspective. You would think, you know, there's some kind of you know, it's not perfect, so I don't think he's going to rate himself 5 out of 5, but he saw that he was able to, you know, sort the bottles he was able to wipe down the board's like you would at the school.

Jaimee Perea 10:03

So, and I think that's a perfect picture of how recovery is so different for everybody and (inaudible) is good. And if he can get done what he needs to get done, you know, he's an example of somebody who's (inaudible) a little differently.

Bill 10:17

Yeah, I can relate to that because people would ask, me how I was coming along, and I would always say 95% The first time I said 95%, that was nowhere near 95%. But in my mind, I was 95% better. But then I realized, reflecting a year

later, reflecting my original comment of 95% better, I realized then that I was nowhere near 95%.

Bill 10:41

But that thing that I used to tell myself in my mind made it enough for me to feel really good about the fact that I'm back at 95%. Like, that's pretty good. I was struggling so much, but I associated my recovery with being further along than it was. And I think that's a good thing if I can confuse myself or trick myself into thinking that I'm better than I am, why not? Share with me one, the number one, or the first tip that we can share with stroke survivors.

Stroke recovery tip 1. Be Intentional

Suzy Burns 11:13

So the first tip we came up with was, to be intentional. One thing I always tell people is that maybe everything's not as automatic as it was before the stroke. And so that can be, I always give the example because of my background in thinking and cognition. And so, many times, we'll go on autopilot and just go, and we're not intentional about what we're doing.

Suzy Burns 11:36

And one example I give is, you know, I'm going to the grocery store, I'm going to go to a different grocery store than I usually go to and then it's on my way to work, but then I end up going into my regular grocery store that I go to every week, and then it's 15 minutes out of the way this direction.

Suzy Burns 11:57

Someone gave me that example one time and it was just a perfect example of what autopilot might look like. So being intentional, like taking that extra time to be intentional about what you're doing in your everyday life.

Jaimee Perea 12:09

And I think about it too is you know when you're using your hand that may not work as well now as it did before you know your affected arm is used to be intentional when you use it, because it's not automatic. You know, your left arm might be the one that's now your dominant, and taking over it's quicker and it's easier and so it's going to be automatic. And so like Suzy was saying, we just have to be intentional and plan out those times really when you're going to use it and

make it a more effortful but more intentional.

Bill 12:38

Yeah, that things both of those things that you said I can relate to. So when I finally was allowed to drive again after several months after my brain surgery, I went and picked up some groceries at a local shopping mall. And I parked in a spot where I normally don't park the car and then I could not find the car.

Bill 13:00

And it took me about an extra half an hour to 45 minutes to walk around the entire parking area, so I could finally find my car. And I just couldn't join the dots as to where I parked my car and my memory. I can't say that my memory was that badly affected by everything that I had been through.

Bill 13:23

But it was such a drama to get back to the car and talking about, you know, which hand you're going to use for what things I remember early on, one of my therapists said to me, when I wake up in the morning and brush my teeth and do all that stuff, I always use my left hand which was my affected hand always use my left hand to do all of those things with even though I don't normally use them.

Bill 13:49

So I would try to eat with my left hand. And it was a massive challenge because I don't normally eat with my left hand. And now I had to use it. I couldn't get it some food was going everywhere. toothpaste would end up on my eye, I would poke myself in the eye so often rubbing my eye instead of getting it to my eyelid or just under here, I would get it into the eyeball. So it was a bit of a drama.

Suzy Burns 14:13

That's a good point though like somehow embedding it into the routine too, and being intentional about what that routine might look like. So like you, for instance, use your left arm to help you get ready in the morning. So being intentional about like, well, this time of day, I eat breakfast and I'm going to use my left hand or whatever that might look like to each person is going to be different for everybody. But I love that example.

Bill 14:40

Yeah, tell me about tip number two.

Stroke recovery tip 2. See The Possibility In Things

Jaimee Perea 14:44

Seeing the possibility and things and knowing that you just because it's something you know, taking out the word I can't. I think and doing things that are still meaningful to you, and identifying what those you know, those roles are that you want to get back to. Those routines or those patterns, whatever it is that you want to get back to and knowing that you can do it, it's it may be finding the right supports, it might be finding a different way to do it. It might be finding some equipment that helps you achieve it. But it's possible.

Bill 15:15

Yeah, I came across this author Carol Dweck who writes about a recovery mindset or a growth mindset. And she talks about the power of yet. And that really sort of changed my thinking in that, okay, so I can't do that yet. which sets us up or sets the brain up for maybe with down the track, we'll still be able to do that then.

Bill 15:46

And we'll get to there at some point. So the power of Yet and I found that with coaching people, as a coach as a, somebody who coached people before stroke and now also stroke survivors. I talk about, okay, you can't do that yet. And what will it look like when you can do that in the future so that there's an idea there's a picture in their head about what that might look like, going forward, you know, so I love what you said.

Jaimee Perea 16:18

I like fat yet. I think that's special because, you know, you see that being such a limiting factor, like a self-limiting factor to saying, well, I'm not going to remember anyway. We'll try. You know, you're not gonna remember unless you give it a shot and you find a way to remember, have some things in place to help you.

Bill 16:37

Yeah. And if you tell yourself, you're not going to remember, you're more than likely not going to remember but if you tell yourself you might remember you might.

Bill 16:46

All right, next, step number three.

Stroke recovery tip 3. Set Goals



Jaimee Perea 16:53

And the next one we wrote down was setting goals. So even if they're small, many steps It gets challenging sometimes because sometimes after a stroke, it feels like, especially in the beginning phases, you're taking these huge strides and making these huge, you're just making so much progress but then some days It feels like you're taking steps backward too and like I've said this so many times already on this podcast but every stroke is different to everybody's injury is different.

Suzy Burns 17:26

But just making those small goals and tracking those goals even as you're into the chronic phases of stroke recovery is just tracking where you're at and keep making those goals to keep progressing because you can still progress you still progress so much beyond when therapy when you still have access to therapy.

Jaimee Perea 17:29

So in comparing it, you know taking where you are today and always looking back, like that reflective piece is so important because if you get stuck looking at today and you're like looking at all the things you can't do you know, yet, hopefully.

Jaimee Perea 18:03

But looking back at where you were yesterday, what do you do differently today or looking back three years ago, you know, what was hard then that's a breeze now, and I think recognizing too that recovery isn't linear.

Jaimee Perea 18:15

And so setting goals will keep you moving forward. But you know, a lot of people when they think after stroke, that their progress is just going to go in a straight line when really, like Suzy was saying, you know, it's ups and downs and backs and forward, and it's all over the place. And sometimes you wake up and you feel like you took a year back, you know, and, but then you're okay. And so I think just recognizing that there are good days, bad days, good times, bad times. But overall, there's a general trend better.

Bill 18:42

Yeah. I love that. You know, one of the issues that stroke survivors I think have in recovery, especially when they're doing occupational therapy and they're in the acute phase is that often we're being helped and supported by occupational therapists, who are very young and early on in their learning. And this is a big drama because of course with age and more hours in the job and more learning and more studying, etc, they're better overall, occupational therapists.

Bill 19:15

And it takes time for them to get this, I get it. And the people who have been around for 10 or 15 or 20 years in the administration office, they are sending, you know, the orders out to the floor, you're working with that person, you're working with that person, this person is doing that today, whatever they're setting the timetable and managing the budgets and all that fun stuff.

Bill 19:36

And I think we miss out on the opportunity to, you know, to recover with those amazing brains with 20 or 30 years experience behind them and setting goals. I was lucky because I had amazing occupational therapists, all the people who helped me were amazing. But setting goals was a crucial part of my recovery.

Bill 20:04

And one of those little goals that I set was the ability to run across the road. And one of my therapists asked me, What do I want to do in my recovery? How do I want my recovery to proceed? Right? I just said to him, look, I've come to a

fairway. But I do want to be able to run across the road in case there's a car coming, and I don't want to get hit by it.

Bill 20:28

Oh, then he goes all right. So not a marathon. None of that stuff. I said, I just want to run 150 meters. I'm not sure what that is in yards or feet. I just want to run 150 meters to get across the road. And that's it. I'm done. So we walked we worked on that and he did exactly what you just said. He filmed me walking fast and then attempting to run because I had this perception in my mind that I wasn't running correctly.

Bill 20:58

Therefore I was afraid to fall. injure me, so I didn't do it, I needed somebody to show me otherwise. And then he showed me the video and he said, Look, you have a very good running technique. Your technique is not an issue, it's just about the proprioception issue, which is your leg does not understand where it is.

Bill 21:20

And we just got to teach it a little bit about what the difference is between running, what that feels like, and what walking feels like. That's exactly what we did. And then we compared a month, two months later, to the first one. And then I felt comfortable with even getting on a treadmill and starting to run again. And I never ran for more than just a few minutes on a treadmill. But that was enough to make me feel like I had accomplished this goal, which seemed little, but was massive.

Intro 21:52

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 recover? What things should I avoid? In case I make matters worse, doctors will explain things that obviously, you've never had a stroke before. You probably don't know what questions to ask.

Intro 22:17

If this is you, you may be missing out on doing things that could help speed up your recovery. 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 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 22:41

They'll not only help you better understand your condition and 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.

Jaimee Perea 22:55

Yeah, it's interesting seeing those comparisons I think it raises the insight into it because You know, when it's just left up to you, you think about like you're saying, Oh, you know, it wasn't very good or even now you might have said, like more recently after all of that therapy, oh, it's still not very good. But then you see it from an outsider's perspective. You know, it brings a whole new, perspective to it.

Bill 23:16

So we do need, other people's eyes reporting back on what's happening for us because we don't know, I'm not sure the best judge of where we're at. That's just the way that it goes. And that's not a bad thing. But that's great that we have this support there. So tell me what's the next step?

Stroke recovery tip 4. Repeat Repeat Repeat



Jaimee Perea 23:39

We put, repeat, repeat, repeat. Everybody's favorite, you know, we think you

know, our brains love repetition. And if you think back to all those beautiful principles of neuroplasticity, and how our brains change and grow and how those neurons relearn and fire, repetition.

Jaimee Perea 24:03

And the more repetition we can get, the better. So, we're talking a lot about embedding stuff in the daily routine, like we were talking earlier with, you know, being intentional, but putting things in your daily routine so that you get more repetitions just like it sounds like you did not have you brush your teeth and eat just to get all those repetitions of lifting your hands to your mouth and grasping onto things and you know, what better time than our daily routine when we pinch about 50 things in the morning, that's 50 repetitions of exercise right there and our brain is just firing.

Jaimee Perea 24:36

But you know, and it could be something small, it doesn't necessarily have to be, you know, brushing your teeth every day, could just be focusing on bringing your arm up to the table every day. You know, getting those types of repetition or remembering a couple of things from your grocery list rather than writing them down every day. Or every week and just getting in those little repetitions as you're able.

Bill 24:56

Yeah, but Susie, how do you make it fun? Because it's so boring.

Suzy Burns 25:03

We're talking about a research study that looked at like how many repetitions people get during therapy, and how many are required to improve their function for art use. And it's such a dramatic difference between the number you do when there are versus what these animal studies are showing you need to have done to improve motor function.

Suzy Burns 25:26

But to make it fun, do things that you love to do. Do something that you enjoy. Maybe it's painting, maybe it's I don't know, whatever is important to you. Just make sure it's important to you. You don't want to feel like you're repeating something mundane and just trying to get these exercises because if it's embedded in your routine, I mean, that's the last thing you want to do. I'd cross

that off of my routine if it wasn't fun.

Bill 25:57

I love what you said because again, this is all triggering my time back in rehab, I spent a month and a bit there. So one of the things that my OTs asked me was, what would I like to do again, and it was around me, they potentially picked up that I was bored with the usual stuff. And one of the things I said I didn't know if they had to pool, in the facility was do you guys have a swimming pool?

Bill 26:22

And they said we do. Can I use that to work in and they said, yes. So that's it. That's why I'd love to do that. And why I did that was because A, I love the water. I had never been back in the water. I hadn't been back in the water. And it was summer. So I was kind of feeling like, man, it would be nice to be able to get back in the water.

Bill 26:43

And then it made it possible for me not to be afraid of falling. And that was a big deal because of course, everything else that I did. I risked falling and I had to have people next to me the whole time. Getting in the pool gave me that first glimpse of independence and I've got nobody around me and I can't fall and it won't matter.

Jaimee Perea 27:06

Sometimes, you know, it's those things that you like doing and you get lost in doing and you don't realize you're like, oh, I've already gotten 50 reps in, and I was spacing out because I was just having so much fun doing the activity, you know, you probably are doing laps and walking around in there, and you're in there for, you know, good 30 minutes, whereas if you're on the treadmill, I'm pretty darn bored. You know, it's finding those little things that people love doing and kind of injecting the therapy in there, you know, injecting the skills in there, to make it fun.

Bill 27:36

Yeah. And then I was looking forward. I was looking forward to going to therapy. And even though I was sitting in my you know, in the ward and my bed and just, you know, staring at the walls all day and watching terrible TV, and all that kind of thing.

Repetitions for Neuroplasticity

Bill 27:52

I would have preferred to not get out of that little cocoon to go and do a terrible exercise or something boring. I would just say no I'm all right over here you know, I've picked up a series of shows or whatever, and I don't need to go anywhere. But I'm fascinated about the work that you looked at or you spoke about Suzy with regards to the repetitive, what's required for neuroplasticity to start to take hold. So, how many repetitions are required? And what do you see like in the animal studies and give us a little bit of info there?

Jaimee Perea 28:30

I wish I had written this down. I had it in memory. I don't have it offhand. I want to say that the number of repetitions that happen during a session is less than 100. I even want to say it may be less than 50. Whereas in a lot of these animal studies, they're showing over 1000 repetitions per day. So, I can get back to you on that with the exact numbers.

Bill 28:57

Yeah, that'll be great. I've seen video footage of neuroplasticity happening in the brain. So there's some on YouTube, you can just type in neuroplasticity. And then, there's micro. I don't know what the terms are, but you know, really, really powerful microscopes that zoom into neurons and they're firing and how they're firing and all that kind of stuff.

Bill 29:20

And I think that's amazing. And there is this understanding that neuroplasticity is something that happens and it's easy, and it's, you know, really good, but it's the analogy that I like to use is, it's like an amazing tennis player, you know, the world's best tennis player. They've been playing tennis for the entirety of their lives.

Bill 29:42

You know, they probably picked up the racket when they were first three or whatever. And they're still training at 35 to be the best tennis player because they realize that if they don't use it, they lose it. And it's a lifelong process. Isn't recovery after an injury from a stroke or any other neurological injury, not something that you do for 10 minutes, and then everything's good?

Jaimee Perea 30:08

It is a long-term process. I like the example you gave when we were just talking about something with tennis we were just talking about musicians earlier too, and how there's a lot of research coming out that's talking about these musicians who are just practicing and practicing and practicing because it's what they do and playing their instruments and it changes the whole makeup of their brain.

Suzy Burns 30:31

You know, they have a cerebellum that is extremely complex. It's kind of you know, there's an interesting is about neuroplasticity, but there is a study out there that was looking at the difference in brains between a taxi driver and a bus driver. I don't know if you've heard about this, but I know it's interesting, right?

Suzy Burns 30:46

But they were talking about how the parietal lobe which is where like a lot of our spatial relationships, all the information is processed. Well, bus drivers, you know, they go back and forth. They go back and forth. They go back and forth. They don't vary where they're driving, and so their parietal lobe is a lot less complex than a taxi driver, especially probably one in New York. Driving all over the place. And you know, taking different turns taking shortcuts, you have to know the lay of the land, there's a car accident here, let's take this back road. So their spatial perceptions and all of that parietal lobe is just firing all the time. And so their makeup, the physical makeup of their brain is different and much more complex in different areas.

Bill 31:27

Wow, that's fascinating stuff. We could talk about this for hours and hours. to five and I'm sensing multiple episodes coming in the future. Because I could talk about this for hours. And there's not enough talk about this type of thing because I think stroke survivors gloss over the importance of these topics that we discuss.

Bill 31:48

And that's understandable because they've got other things on their plate, right? But if the curiosity is there for stroke survivors that are listening or watching right now then these are really important things to understand. Even though it seems trivial, that a bus driver's brain looks different from a taxi driver's brain, it's not trivial.

Bill 32:07

Like it's a really important thing. And you could potentially adapt that knowledge to support your stroke recovery. Because if I had a stroke survivor, and I was an occupational therapist that I was teaching how to walk again, and now we're a taxi driver, I would be using that to talk to them in a language that they understand about, alright, so you can't lift your cup with that hand in this way. How can't we go around the roadblock to find another way to lift that cup, you know, and just let them work it out? And I'm sure that they'll come up with ways to work it out.

The OT Sisters 32:47

Exactly.

Bill 32:49

Tip number five.

Stroke recovery tip 5. Build Your Team



Jaimee Perea 32:52

Tip number five is to build your team. So we're more familiar with healthcare in the United States, but Something that we found interesting is that in the United States and I know other countries as well, we emphasize independence. And you have to be able to do this independently, you have to be able to do this independently.

Suzy Burns 33:13

But there are a lot of other countries and regions out there where they rely a lot more on families and the families there to support you after you've had a stroke. And so, one thing that we would say, especially to the population that we work with here in the United States is it's okay like use your family, use your friends, use your church community, use these people build that team to help you and support you and your recovery. It doesn't all have to fall on you being independent in whatever it is like and maybe it is important to be independent in this task to you but, use your support.

Bill 33:49

I love that, build your team because my parents are amazing people and they helped me so much. But if I had to use them for everything, thing in my recovery, I would become a terrible son. Because I couldn't deal with it I couldn't deal with it and I talked about it lovingly and with a bit of fun. I talked about my dad, he was my driver for the most part, you know, when I was not allowed to drive, he was my driver. And I just talked about how he couldn't do anything. So he dropped everything to be my driver. And that was such an amazing thing. But the fact that he was my driver drove me bananas because he's such a shit driver.

Jaimee Perea 34:33

Like you in the passenger seat either go slow down. Stop there. Why aren't you turning this way?

Bill 34:39

I couldn't tell him he was a shit driver. I just thanked him every day for everything that he did for me. But you're right. It's about building a team of finding other people to bring in to also help with some of those challenges, right?

Jaimee Perea 34:53

It's also a gentle balance, too. We were talking about this too, that you know, but not to rely too much. You know, there are things that you can do on your own. Do it Because like you're saying, if you use it, if you don't use it, you lose it. And so you want to keep getting better and keep inching toward where you want to be. rely on people, but don't over-rely on people.

Bill 35:10

Yeah, I have a little course that I'm gonna make available to some people it was done as a webinar a little while ago, it was called The Road Back From Stroke.

One of those steps is that build your team.

Bill 35:25

And I found that that has been something that people have related to actually understanding what the team looks like. It's not just medical people. It could be non-medical people. The church is a really handy one. And that's just for the emotional stuff, you know, all of that. Why am I alive kind of conversation?

Bill 35:43

So, I think for me building my team was helpful. I had in my team, obviously, my neurosurgeon, who I dealt with on a very professional basis. I had my occupational therapists that were in my team for probably eight or nine months, and then I was able to move away from that part of my team, I had my parents, I had my friends who would come out and take me to places that I wanted to go to that I hadn't been to for a while, of course, I had my wife and my children, every part of those, every one of those people was my team.

Bill 36:15

And I didn't burden one person with all the tasks, which is another important thing that carriers do so tough, and what you don't want to do is give them the task of being everybody in that team because most carriers will say yep, okay, I'll do that as well and out of guilt or whatever it is, and then they'll end up neglecting themselves.

Jaimee Perea 36:38

It's true. You know, there's there's a lot of studies and things on burnout too. And so caregivers need to take care of themselves.

Bill 36:45

Tip number six,

Stroke recovery tip 6. Educate Yourself

Jaimee Perea 36:47

Educate and advocate. We put educate because, you know, educate yourself. And that's the foundation of so much. We know that the more that, do you even know what type of stroke you had? Is half the battle and knowing where it affected your brain? That gives you so much power in just your knowledge and being able to advocate, you know what medications you're on, because that's how you can

advocate for being on different ones or lowering your doses or advocating for more therapy, or, you know, it is the foundation of a lot of the recovery is seeking out those resources.

Suzy Burns 37:28

Even myself, and I mean, I haven't had a stroke, but when I go into a physician's office, a lot of times I automatically even though I have a healthcare background, and I have a lot of knowledge around it, I still will fall back into that patient mode and listen to what the physician has to say. They're like that kind of hierarchy. Like all-knowing I'm the patient, I do what you say. And so coming equipped to those visits with maybe taking notes or writing those questions out ahead of time, and just bringing a teammate with you.

Bill 38:05

Yeah, the teammate's things are important. And doctors annoy me so much sometimes. And without him, I wouldn't be here. So credit where credit's due no problem. But what is it with doctors and you guys, I would hope you get cranky. Like I get cranky. What if it was doctors who say stuff like, they probably won't walk again?

Suzy Burns 38:34

That's hard because I think a lot of times, they're asked really hard questions too. And, I had so many people who have come to me and I know you have too Jamie that has said, well, I've been told that I'm not going to walk again or I'm not going to be able to use my arm again. And then months and years later, they like I find it almost motivating to some people like I'm going to prove them wrong and I'm going to do it.

Suzy Burns 39:02

So, I mean, I hope that people can turn that around. But I know it can be so disheartening to hear that. But I hope it's also motivating too.

Jaimee Perea 39:15

I don't like the time stamp. That one is the hardest one for me to hear when people come to me and say, hey, it's been three months since my stroke. That's it, my windows closed, I might as well not try and I'm like, stop, stop right now. I had somebody come to me the other day and say that my student was in the room, and he got partial through his sentence I said no, it's not real.

Jaimee Perea 39:37

And my student looked at me like, how did you know what he was gonna say? I was like, it's because of the time-stamping it's, it's overused and it's not true. You know, people have the potential for so long to keep getting better. It's not a three-month six-month year window. You know, there are, like you said strides in the beginning it may slow down, but you still have great potential. And so that's one of the hardest things that I hear is the time stamp.

Bill 39:59

Yeah. I am going back to what Suzy said earlier about educating and advocating. Like I've got a download people can come to the website, and they can get a free download. It's called seven questions to ask your doctor after your stroke.

Bill 40:12

And it's about that it's about taking and I don't know if those questions are even helpful, right? I assume they are. But it's about just going there and having something that you can do as a stroke survivor, that you couldn't do before because you don't know what to ask or where to start and that might jog in their memories, something else they want to ask and create a conversation that wasn't going to happen before.

Bill 40:35

People can go download that for free right and print it off and just take it in and just ask the doctors those questions. And the thing about the doctors going back to that is the timestamps and the generalized responses to hard questions is that they spend so much time, money, effort, and resources to plug our brains back up to get us back on our feet, to get us out of the hospital, and then to say, you probably won't walk again?

Bill 41:12

No, no, no. That's the last thing you want to say when you've spent so much time, money, effort, years studying. The last thing you want to do is give your patient as they're wheeled out of that hospital you want to do is undo all your good work by saying you probably won't walk again.

The OT Sisters 41:33

Yeah, crushing someone's home. Yeah, they're on their way to rehab.

Suzy Burns 41:40

It's hard. It's hard for me to hear stories like that.

Bill 41:43

Yeah. So it's just like something that I'm gonna keep saying and keep saying in the hope that one day, one of those doctors has turned into one of our episodes and can just go oh, okay, I won't do that anymore. What is step seven?

Stroke recovery tip 7. Be Your Advocate

Suzy Burns 42:01

Well, our step number seven is to be well, and so be well be healthy, not only thinking about preventing another stroke, especially like if you've had a stroke, you are at risk for a higher risk for a second stroke. And so different ways to prevent that.

Suzy Burns 42:21

So, nutrition, and physical activity, not only help with prevention, but they also can help with recovery too. So a lot is coming out lately on the benefits of physical activity and cognitive function. And even if you're starting to think about cardiovascular health and brain health and what that might be, be well as far as nutrition, physical activity, and.

Jaimee Perea 42:47

Going back to sleep Is something that a lot of people overlook, and that's something that we put down as one of the main priorities on our Instagram was a section about sleep because it's something can and a lot of times heavily medicated and there can be little things that you can do to help with sleep and your sleep quality.

Jaimee Perea 43:07

And then of course mood and knowing that, you know, you might have changes to your mood like depression, you might feel down you might feel blue, you might feel anxious, stressed, and finding some good solid ways healthy ways to cope with that. And you know, speaking with your physician or, or counselor, or something is needed for that as well.

Bill 43:26

That's brilliant. I love it to be well. And by being a well, that means looking at your nutrition, looking at your sleep. Those two I think are probably the two

biggest things that made a difference in my life. And in my recovery, when I was able to get to sleep for longer amounts of time, I was able to feel way better when I woke up the next day which would, as a result, support me in overcoming fatigue, further along in the day, like you know, after a few hours or four hours or whatever it was later on in the day.

Bill 44:07

And then eating well also supported me to help to overcoming fatigue. Now, the diet that helped me the most, which is something that I've benefited from greatly, is combined with, you know, getting more sleep was a low carb diet, a diet that didn't include highly processed bread, and sugars and processed cereals and all that type of thing.

Bill 44:29

So that made a massive difference to the way that I was able to feel after that meal. I wasn't getting those food coma experiences, which as a result helped me get further along in the day as well with decreasing the amount of fatigue.

Suzy Burns 44:45

Yeah, I would agree with that. And I've heard good things. While I'm not a nutritionist, my background is actually in nutrition and dietetics that's what my bachelor's degree is in. So I'm very passionate about nutrition and healthy eating and how it can help with recovery too. But yeah, a couple of diets. Of course, the low carb has been really helpful for a lot of people. I always hear about the DASH diet too.

Bill 45:12

Tell me about that one.

Suzy Burns 45:13

Yeah, that one is a big recommendation, at least here in the US. It's more about lots of fruits and vegetables. Similarly, lots of whole grains, lean meats, and dairy, they used a lot to prevent or reduce hypertension. That one's kind of foundation of that one. And then another one that we see a lot of is that anti-inflammatory type diets, like a Mediterranean type diet is another one that they tend to recommend.

Bill 45:44

Yeah, awesome. Combined, you guys have got in my mind, the ideal combination

of things that stroke survivors need to get on a really good path to recovery. When I first started going through my stroke journey in 2012 there was no information out there about what anyone could do to heal, recover to overcome. And to get that information if there was some you had to spend a lot of time researching.

Bill 46:16

I spent tons and tons of hours researching and trying to find people to help me because my doctors couldn't answer simple questions like this because it's not their thing, right? That's not what they do. And I used to get frustrated. So combined. I feel like you guys have got a very good foundation and sort of broad depth of knowledge, that all those things bringing them together make a massive difference to stroke survivors. So well done for that. Also, then, what's the next step are we up to number seven?

Stroke recovery tip 8. Be Well

Jaimee Perea 46:54

Eight. We must be kind and patient with ourselves. We saved that one the best for last because we agreed it was most important because it's a journey and it's not a couple of steps that will get you better it's a journey and being kind to yourself along the way is important and we know that it's not a smart thing to there are so many things out there where you can compare yourself to other people or see somebody getting better at a different rate than you are but you know, be patient with yourself and set those mini goals and you know, just continually strive to better yourself and but also be patient with yourself along the way.

Bill 47:33

Yeah, being kind and compassionate to yourself is such an important one I was hard on myself before the stroke into that, you know, I had all these goals, always compared myself to other people doing better in business or making more money or doing this or doing that and it just made such a difficult life it made for such a stressful life that was caused by me.

Bill 47:56

I thought it was external people or things causing it but it wasn't, it was me. And when I was able to stop being kind to myself and realize that, that process, the way that I used to go about life wasn't going to support me going forward because

I had to deal with all these other complications. You know, memory issues, fatigue, all that kind of thing.

Bill 48:15

I started to get comfortable with the fact that if I'm nicer to myself, and I wasn't my harshest critic, then I'll be able to flourish in that space and allow myself the ability to screw up and the ability to be wrong and the ability to take the wrong step. And giving yourself a break, I think makes a massive difference. In the way you feel physically, the way you feel emotionally, and the way you feel mentally.

Jaimee Perea 48:46

I heard a quote one time and I thought it resonated, but I may not get this hundred percent they had said, Would you be friends, with somebody who talks to you the same way that you talk to yourself? I thought that was super powerful. You know, just be nice. Make friendships with yourself, you know?

Bill 49:09

Yeah.

Suzy Burns 49:11

Yeah, focus on problems and it's easy for anybody to focus on the negative and, just be kind to yourself. It's okay. If you work hard one day and the next day, all you want to do is take a nap all day. That's okay.

Bill 49:33

And it is, it is. And it's not only is that okay because it's okay. It's also okay because it's probably really necessary in your healing. It's how we heal, right? And that means if you're wasted, and for one day, you've got to do nothing. That's well done you are doing a lot to help yourself recover. I remember about two or three weeks into my rehabilitation after brain surgery.

Bill 50:01

So November 2014, was brain surgery rehab until about December 20 something and I'm not sure if it was week one or week five or week four out I can't remember, but there was a guy in there and he was in his job. And I talked about this in a 10-minute presentation that I did here in Melbourne a few years ago.

Bill 50:22

And I talk about the way we speak about ourselves and the language and this guy

I named him Ivan because I can't remember his name. He had the job of moving an empty toilet roll picking it up with his affected hand grasping it and then moving it over to the right side of his body. But his affected hand wouldn't do that in an ideal way.

Bill 50:47

And what he was doing was he was calling his hand a bastard. And as he was doing that and getting more and more frustrated, he was failing to pick up that empty toilet roll more and more and he was failing to put it down where he needed it to go. And because I had been a coach and I had done coaching for many years before that I couldn't resist, right?

Bill 51:09

So I just chimed in and I said to him if your hand did what you wanted it to do, what would it be Ivan? He said it'd be my friend. And I got him to talk to his hand in that way and call it his friend. And he goes, okay, friend, let's do this, something like that. And he picked it up within a moment after calling his hand a friend, he picked it up for the first time, held it on the other side, and let it go. It was the most profound change that I've seen in a human being ever.

Bill 51:45

And in this most difficult time, he had a massive win just by changing one word to another word, you know, so I'll share that with you, and in the show, notes will be the link back to that episode because it's an episode of the podcast so you can see it. And I hope that people who listen to our interview, understand that what you're suggesting, is not really that complicated.

Bill 52:13

These things are not things you have to pay extra for, or you have to do anything more for. You said they have to be intentional. They have to see the possibility in things. They've got to set little goals. And they've got to, repeat, repeat, repeat, or that could be a hard one. But we understand it's important.

Bill 52:35

They've got to build the team around them. And that's just a couple of phone calls, calling in favors to people that you've done favors for before. And they've got to educate themselves and be their advocate. I love that one. That's awesome. And they've got to be well by looking after their diet. Then look after their sleep.

Bill 53:00

And just doing some things about being kind to themselves. So tell me about what's in the future. For the OT sisters, I know that recently you guys have come together on Instagram, as this team of amazing OT knowledge. What do you guys have in store for your practice going forward?

Suzy Burns 53:28

So I think just both of us working so closely with people who've had stroke and brain injury, we know that there's a lack of information and a lack of resources for people. We've had people come up to us and just say, hey, you're an OT, like, can you answer this question for me? And so, what we hope to do is to help survivors of stroke and brain injury become more confident feel empowered, and take an active role in their recovery.

Suzy Burns 54:01

We just started on this venture with our Instagram account about a month in is so very new to OT Sisters but, our goal is to create something and we're working on defining that right now. But create something helpful to people. And they can use this as a resource.

Jaimee Perea 54:24

They can access it because that's pretty limiting too. For people who don't have access to therapy or don't have access to ongoing services.

Bill 54:32

Well, I'm gonna take credit for discovering you then. That is awesome that you guys are so early on in this combined joint venture type thing. That's what we need. We need combined knowledge coming together to see patterns and then bring information out to people uniquely and differently because there's nothing more boring than sitting here on my own doing that all the time every day.

Bill 54:58

No one wants to listen to me talk about myself and how amazing I am, even though I am. And I see you guys are high energy and that's required and important because stroke recovery although it shouldn't be overwhelming for somebody who's going through it, should be something that's energetically charged in a bit of a positive way you know, that's full of life, etc.

Bill 55:24

Rather than dull and dreary your post on Instagram to prepare for this podcast was what excited me about meeting you. Because you guys are doing all the crazy stuff in the background. So I thought I'd met your energy with my technicolor poncho.

The OT Sisters 55:42

I love it.

Bill 55:47

I looked everywhere to find this poncho. When I finally found it. I had to have it. So thank you for doing what you're doing. Thank you for going on this joint venture and bringing more information to stroke survivors, we need it, especially in this time of isolation where we can't go out and be with our OTs as often as we would like, especially when we can't be with our family as often as we'd like and all those other things. We need more people advocating for us and doing this kind of work. So from me to you and from all the stroke survivors thank you.

Suzy Burns 56:23

Thank you for inviting us to speak with you on this podcast today this has been great.

Bill 56:29

My pleasure. Now before we go, if people want to find out more about you guys get in touch with you guys. Or where would they go on Instagram?

Jaimee Perea 56:37

@O.T.Sisters

Bill 56:43

Okay. And is there a website?

Suzy Burns 56:46

Not yet but it is something that we're working on developing.

Bill 56:51

Alright, perfect. When it's up, let me know. So I can send them a link if they ask but thank you so much for being on the podcast.

The OT Sisters 56:58

Thank you.

Intro 57:05

To discover how to heal your brain after a stroke, go to recoveryafterstroke.com

Bill 57:15

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Bill 57:47

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