Stronger After Stroke - Peter G. Levine

As stroke survivors in rehab reach their plateau they are often discharged. Peter G. Levine a clinical researcher says that this is when the real work starts

Socials: https://www.amazon.com/Peter-G.-Levine/ https://recoverfromstroke.blogspot.com/

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Transcription:

Peter 0:00

Discharge from therapy is not the beginning of the end, it's the end of the beginning. After a stroke, you have this area that's dead. And then there's this area that surrounds it, it's called the Penumbra and it heals.

Peter 0:14

And as it heals, there's originally some swelling around it. And that makes the neurons not work very well. They're still alive, but they're not working. They're said to be stunned. It's called cortical shock, there's a technical term for it.

Peter 0:30

But as that all the swelling goes down over the first three months, usually, those neurons start to come back. And as they come back, the person makes quite the

incline in ability gets very intense, they get really good, but at some point, all that Penumbra is back online, and they naturally and it's an occurrence, it happens to everybody they plateau.

Intro 1:01

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

Introduction - Peter G. Levine



Bill 1:14

Bill from recoveryafterstroke.com This is Episode 135. And my guest today is Peter G. Levine. Peter is the author of the book Stronger After Stroke, which is in its third edition. And he's also a researcher, clinician, professor and science communicator.

Bill 1:32

He has spent his career reporting on the best systems for driving post-stroke brain plasticity. Today, we'll discuss what you must do when you've reached the plateau in your recovery, and you have been discharged from rehabilitation.

Bill 1:49

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Bill 2:06

Also, please share your favorite podcast episode on your social media. This will help other people that might be going through a tough time right now feel a little bit better about what the future may hold. And it may offer them hope that there are better days ahead. Thanks for tuning in and listening. And now it's on with the show. Peter Levine, welcome to the podcast.

Bill 2:31

Thanks, Bill. I appreciate it. Thanks for having me.

Bill 2:34

My pleasure. Thanks for reaching out your handle and your blog and everything you do is called Stronger After Stroke. And I love the sound of that. It potentially can be controversial for somebody who's had a stroke to read that and I'll tell you why.

Bill 2:51

Because some people don't feel stronger after stroke, and they're going, What do you know about it, Peter? So with that, in mind me playing devil's advocate, tell me about how you came-up with the name stronger after stroke?

Stronger After Stroke



Peter 3:10

First of all, I love the devil's advocacy going on. And it's a good thing. It's been pointed out before that it's probably not the best name. Some people think, because you're at your worst right after your stroke.

Peter 3:26

But I think that was my point was that if the bottom of it is the stroke itself, then you're hoping to increase after that. So you would be technically stronger after a

stroke unless the stroke kills you, which, unfortunately, it does a lot of people or it leaves them in a vegetative state, or they're completely dependent in a nursing home.

Peter 3:52

But for most people, the bottom of it is something that they can jump off of and become stronger after that. How I came up with the name I have no idea. I don't even remember that far back. The first edition was 2008 probably started writing it in 2005. I don't know.

Peter 4:14

Here's what I will say it's been plagiarized so much I should have probably bought the copyright or whatever you call it on that. Because there's all kinds of groups major universities here have groups that are major neurological journals have named articles stronger after stroke.

Peter 4:35

So it's been plagiarized a lot but I think it does have a catchiness I'm hoping that people can get stronger after stroke. I will say that you're right. The blog is called Stronger After Stroke. The book is called Stronger After Stroke. And my email is strongerafterstroke@yahoo.com. So it's like a one size fits all catchphrase.

Bill 5:02

It's a good one. I like what it potentially could inspire in somebody. And I don't necessarily feel stronger every day after the stroke that I had, but I do feel like I am better for it. And that stroke is one of the best things that ever happened to me, and that's something that I am working on.

Bill 5:24

And I'm finding, there's a lot of stroke survivors that can say that, and there is a lot of similarities in the, how they get there, I'm doing my own little research project on how was that people managed to get there, and I feel like, soon we'll be able to take people through a process to teach them how, what the steps are, to be able to say, stroke's the best thing that ever happened to me, regardless of the deficits that they live with, or experience.

Bill 5:49

So your heading does inspire me to be stronger after stroke, as well, as potentially seeing myself in those early days as somebody who would say, you know, what, do you know, Peter? As if you can be stronger after stroke. So I love how it plays, at least in my mind, it plays games of context, and where I place it and how I talk about it.

Bill 6:16

Now, you're a clinical researcher. So I'm going to make the assumption that in 2008, or whatever it was that you came-up with the name or wrote the book, I'm going to make the assumption that you saw that some people are experiencing a stroke and then coming back stronger. So tell me a little bit about your background and the kind of work that you do and how you ended up in stroke work?

Bill 6:42

Yes, so I started out. I got a bachelor's degree when I was supposed to after high school. And it was in communication, something completely unrelated. My real area of interest when I was getting that degree was I was a drummer in rock bands. And so I was very interested in bands, the bands I was in.

Peter 7:07

But when I graduated, I moved to a town here in the United States called Austin, Texas, which is very well known for its music. And I was living in Washington, DC at the time, and the music career just wasn't going anywhere. So I graduated from college, I made that commitment.

Peter 7:25

I moved to Austin, Texas, got into a band very quickly after that, then very quickly got signed to a major label. So MTV, I don't know if you guys have that. But MTV touring major label albums, the whole thing. And in a lot of ways, that ability to understand what it takes to be a good, maybe better than good musician is the same thing that stroke survivors have to do, in order to get stronger after stroke to get better after their stroke.

Peter 8:02

It's the same, absolutely the same process. And I've gone back and watched a few of your videos about your sort of obsession with neuroplasticity. That's what it's all about. That's what athletes know well, that's what musicians know well.

Peter 8:17

In any case, you know, I was on the road for quite some time with this band, and

then we parted ways because it wasn't a great lifestyle for me, really had nothing to do with sex and drugs and rock and roll as much as it had to do with dietary things and not getting enough sleep and all that stuff.

Peter 8:37

So I went back to school, got a degree in physical therapy, and worked clinically for a few years, worked with stroke survivors, and then got an offer for a job in clinical research at the Kessler Institute, which is a big hospital here and in the states that has a very big research arm.

Peter 8:55

And I had three bosses at the time, something I would definitely suggest to anybody to not have more than one boss. Maybe one boss and one wife, and that'll do it, anything more than that is too much. I had three bosses at the time. One was the chief vascular surgeon in New Jersey, one was a PT, PhD Sue Ann Sisto, who's still in clinical research.

Peter 9:21

And then my boss and then a colleague and now a friend of mine, a friend the whole time. Stephen Page, who is an occupational therapist now, but was somebody that was working on his PhD anyway, it's a long story, but what I'm trying to spit out here was my friend Steve, who was getting a lot of the money for our research into stroke was a very high-level swimmer in college.

Peter 9:50

So when we got we started in 1999, and we started in this small portion of this very large lab, and we had an athlete and a musician looking at stroke recovery. And Kessler was funding some studies, the NIH was funding some studies, we got some other funding.

Peter 10:10

And the question became, what the heck do we look at? So for a long time, therapists have thought that if they put their hands on you in a certain way, and they handled you in a certain way, they're called handling techniques, that was the zenith that was the best that you could do for stroke survivors.

Peter 10:32

You would handle them, and then somehow, that would transfer into great movement. To an athlete, that makes absolutely no sense. Because you never have a coach handling you, you know, that coach would get punched in the face after a while. That's what I'm saying, coach don't touch me.

Peter 10:51

Musicians are the same way, you don't have a piano teacher with their hands over the hand of the student. So we didn't think there was a lot there. But what we did find some traction on was what athletes did, to get better at their sport.

Mental Practices

Peter 11:11

And my colleague, Steve had been a very high-level swimmer. And the first thing he wanted to look at was mental practice. Mental practices like mental imagery. So if you're going to be a swimmer, or you're going to be a gymnast, or you're going to be a musician, you would mentally practice the song, or the swimming, the stroke, the routine, whatever it is. And that would do something in your brain and make you better at whatever that skill was.

Peter 11:41

And he came to me in 1999, and said, Look, I want to do mental practice and stroke survivors. And I said, you shouldn't do it, Steve, because you're going to end up wrecking your career. Because if you do it, you're going to take this very soft thing, mental practice, whatever the heck that is and you're going to put it up against dense hemiparesis.

Peter 12:03

And it's going to get its butt kicked, and your career is going to end before it ever starts. So about a couple months later, he came up to me and he said, look, I really want to do mental practice in stroke survivors. And I said, Steve, we talked about this, you're going to wreck your career don't do it.

Peter 12:19

And he said, well, we got funding. And I said, let's do it, it came down to funding. So we looked at mental practice. And here's something that I'm sure people that have stroke would be very interested in. If you mentally practice something, some movement that you know, well, the portion of the brain that lights up is exactly the same portion as if you actually do it.

Peter 12:43

Not only that, but the muscles involved in that movement will fire their fire, very minutely, but in the same order and for the same duration as if you actually do it. So let's review, you don't even have to do the movement, all you got to do is think about the movement, the muscles fire, and that portion of the brain dedicated to that movement lights up.

Peter 13:04

The new research now says that you don't even have to go that far. If you observe somebody doing a movement, and they're doing it well. The portion of the brain, if you're watching them, that portion of the brain that's dedicated to that movement in you will light up and those muscles will fire in the same duration in the same order as if you were to do it.

Peter 13:30

So let's review. If you imagine doing a movement, if you see somebody else doing a movement, or if you do the movement, yourself, all three of those drive brain changes, and help recovery. So that was our launching off point athletes and musicians. Thanks for listening Bill that was long.

Bill 13:53

It was good. There's a lot of information in there. Basically, the long and short of it is is that. And this is the challenge I have with the sciences is that they take something that we know to be true in nature, and then they take 20 years to explain it and then prove it before it can be applied.

Bill 14:14

And one of the issues is that think about every child that has ever been born, that has walked. It has done that by seeing every other person around them walking and it's going, I can do that. Or I want to do that or how do I do that. And it drags itself and it uses its arms and it uses legs and it does all these things and eventually, from its knees or from its belly or from its butt wherever.

Bill 14:41

It gets to its knees and then from its knees. It has this next transition which is to walking and somehow it knows to get to the knees before it gets to walking but somehow it knows when it gets on its feet, what has to happen? If you fall over what you have to do is you have to get up again and you have to just find a new way to do it, strengthen the muscles do all those things.

Bill 15:03

So I dislike that about science. But also I like that about science because for the majority of us we're a massive head on shoulders, and we need to be convinced at the head level that something is possible before we can take it and embody it and actually take steps and do it.

Bill 15:22

What I love about what you said is that it's the lazy man's way to get better at stuff, it's you don't even have to do anything you don't even have to put any effort in. All you got to do is imagine yourself. And if you can't imagine yourself, get somebody else to help you imagine yourself by talking you through, you know, the process of for example, I do this with people that I coached, close your eyes, imagine yourself doing this thing, pay attention to your leg, pay attention to your arm, pay attention to your gait, your body, your position, where you are, how it's feeling.

Bill 15:56

Breathe, and then from there, take them out of that. And I know that what I've done is lit up or created new neural pathways that they can then access when I'm not around to achieve the same task. And I put a lot of time and effort into that myself when I actually couldn't walk after my stroke.

Bill 16:17

And what happened to me was, I had a AVM that started to bleed in February of 2012. Then bled again in March of 2012. And then it bled again in November of 2014. And then my surgeon said, we have to have surgery, you're at risk of this thing bleeding out and causing a lot of damage or death, it's safer to have, the risks are lower if you have the surgery and then we'll deal with whatever it is that you have to overcome after surgery.

Bill 16:50

So when I woke up from surgery, I couldn't feel my entire left side, my proprioception was out and I had altered sensation on my left side, which I still live with, I still have. And I was waiting for at least a week before I could actually get into the physical rehabilitation room where two therapists would hold me up or they would attach me with the crane to the ceiling to make sure I didn't fall over.

Bill 17:17

And in the rest of the time, while I was waiting, I was using guided meditation to imagine myself walking, I was in the bed, in my ward, lying down with my eyes closed, going through this process of imagining myself grabbing the the rail with my left arm, and my foot going in the position that I needed it to go.

Bill 17:41

And it taking over and walking and supporting me and holding me up, I imagined how my knee would not buckle under my weight, and it would support me, imagine how my muscles would interact with my knee and my ankle and my foot. And I just started playing this over and over and over in my head.

Bill 18:01

So that when I got to the first opportunity to actually be supported and guided through this with a physical therapist, I had a baseline I had somewhere to start from and it wasn't all brand new. And I had a week's worth of I'll call it self therapy before I get into actual therapy. So I really love that somehow your athletics and music background.

Bill 18:34

The people that were involved in your, in your team, who had those types of backgrounds, transferred their skills and their knowledge from their other career that seems totally irrelevant when it comes to stroke and applied it in stroke. And that's one of those beautiful things that people who have come from different backgrounds and have had a stroke, already have the skills, they don't realize that they can transform and adjust and apply to stroke recovery.

Bill 19:06

And it's just about getting a little bit creative and perhaps having some guidance into how to do that. So what did you guys learn after the study began and after it was funded and allowed you guys to gather some data?

Functional Magnetic Resonance Imaging

Bill 19:24

Right, so our data really had to do with functional magnetic resonance imaging. It's a way of scanning the brain and seeing if a portion of the brain lit up that didn't light up right after the stroke. One of the interesting things that we found was, as you know, your left side is is the weaker side. So the AVM the malformation, the surgery was on the right side of your head. You have a scar there now is that true?

Bill 20:00

Do it's not visible today because my hair is longer than I

Bill 20:03 see it, I think I see it, it runs from about the crest of your ear to the crest of your head.

Bill 20:08 That's it. Yeah.

Bill 20:12

So, that was on the right side of your brain, and it affected the left side of your body. Now typically, if you have neuroplastic change, it will happen, what they call it in a Peri infarct area right around the area of infarct. So you have the area that's dead, and around that area is the part that comes back and where the neuroplasticity happens.

Peter 20:41

And we certainly saw that with mental imagery, mental practice. But the weird thing that we saw was that the ipsilateral side, so usually it's the contralateral side that controls so the left side of my brain controls the right side of my body, and vice versa. But what we saw was, if it was a left hemiparetic person, often, the left side of the brain would control the left side of the body completely backwards.

Peter 21:09

And yeah, and if you think about it, it kind of makes sense. Look, the brain, we always talk about the mind and the brain, the mind is you, your ambitions, who you love, what you're trying to accomplish, the brain is just the machine that carries it out. We don't have to care about what the machine, how the machine does it and where the machine does it let it worry about that it's good at that.

Peter 21:32

All we got to do is present a situation where we're so over-stressing the affected side that something takes over if it happens to be the ipsilateral side, my right

hand is has a problem. It's the right side of the brain. Why not? It's all good neurology there. We know that neuroplasticity is not about the number of neurons, it's about the number of synaptic connections between neurons.

Constraint-Induced Therapy



Peter 21:57

So let the brain do it on the wrong side of the brain, what do we care? Typically, what happens is it may initiate in the ipsilateral side, but then it migrates to where it's supposed to be. But that happens further down the line. The other treatment option I should talk about that our lab was sort of well known for was I'm sure you've heard of constraint-induced therapy.

Peter 22:25

Have you heard of that Bill? Yeah, so it's exactly what it sounds like, if you had left hemiparesis. So your left side, it was weak. The clinician or really the stroke survivor themselves would wear a mitt on the good side, and then have to live their entire life with their bad side, whatever that they were trying to do, they would have to do with their bad side.

Peter 22:54

Now, obviously, you have to have some movement to jump off because otherwise you're tying up the good arm and they can't do anything with a bad arm and that's just mean. But if you get the right kind of person, you drive huge amounts of brain changes. Because they're forced to do it.

Peter 23:11

It's literally called forced use. We call it constraint induced therapy because we constrain the good side force use of the affected side. And that is well is very much like an athlete would handle things. So I played basketball for a long time, I was never really great, but I love playing it, how I broke my nose and broke fingers and all kinds of.

Bill 23:33 Sounds like you were terrible.

Peter 23:35

It was terrible, it was a disaster. But no, I was good in some ways. One thing I was really bad at. I don't know how it is in Australia. But here in the United States, if you can't do something with a pickup game of basketball, there's people on the sidelines that will say he can't do this, he can't do that he has no hops, they'll yell at you, and it's just like, it's a great fun.

Peter 24:00

Anyway. So one thing that was very clear about my game is I couldn't go left, I could use my right hand and back in the 70s, you could get away with just dribbling right handed. But then every you know, all these great basketball players now everything is bilateral. So I spent about a month doing nothing but constraint induced therapy on myself and only dribbling with my left hand.

Peter 24:24

And I gotta say I got better with my left hand. It still wasn't as good as the right hand, but we're not trying to make stroke survivors perfect. We're just trying to get them better. I think this very high bar that a lot of clinicians set up or that stroke survivors set up on themselves.

Peter 24:41

Every day is a challenge for everybody. We're all getting older, you're just trying to chip away at your present abilities, just like a high level athlete would just like a high level musician would. So those two things started our path, mental practice and then this other forced use constraint induced therapy, both steeped in athletic training in a lot of ways.

Bill 25:05

Absolutely, and again, it makes sense as athletic training is being used to support

recovery of a body part, a leg, an arm, whatever it's part of the body like that's what athletics does is it trains and works the whole body. And if you're applying that type of training to stroke recovery, I think it's a very simple inroad into giving people an insight into remember when you used to play football, or when you used to play basketball, how you trained, and you did a certain thing and you went through a certain process?

Bill 25:40

Well, stroke recovery is just the same. There's a couple of differences in the way that your arm works now. But the idea of coaching and therapy, it's basically the same idea, they name it something different. And that's one of the interesting things about the mindset and getting people switched on to taking recovery down a different path.

Bill 26:04

Is that they think that recovery begins and stops, there's a start, and then there's a stop. When you get to the stop, you're done, you're recovered, and things are better. I've got a coaching client, a stroke survivor, who's a person that I coached through his, you know, troubles and tribulations that stroke has caused, and we're moving towards a better outcome for him and helping him get better.

Bill 26:33

And he has a deadline of seven months out why aren't I better yet? And just yesterday, I asked him, How did you get seven months as being the dates or the timeline by when recovery would be done and complete? Where did you even come up with that? And he doesn't have an idea as to where he came up with that. But many stroke survivors do that they don't understand that coaching in basketball, you could be Michael Jordan, and the best in the world.

Bill 27:04

And when you're playing for the Chicago Bulls, and you're going for that next championship, and the next one, and the next one, the next one, coaching hasn't stopped, because you won the first one, coaching continues. And it continues to get refined and pick up things that you forgot about, for example, from when you were first starting basketball when you were just a child.

Bill 27:29

And we keep reintroducing ideas and refining and refining, so that when you're

20 or 30 years into your basketball career, you're still getting supported and coached and talk through things. And people are paying attention to what you're doing. In case you've missed that you've slackened off on your approach to the ring, or the way that you're defending, you know, your zone.

Bill 27:57

And, and that's the thing, like it's really bizarre that stroke survivors have a deadline, a timeline, and anything that's got to be done by that date. And then I can just go back to life as normal and not have to worry about anything. Roger Federer is in his 40s. He's one of the best tennis players in the world, and he still as a coach sitting in the stand with him every single game.

Bill 28:17

And the coach doesn't not go to one of those games, because Roger will be right from now on, you know, it's really fascinating, the whole mindset around how when I go to recovery, I'm going to get discharged from the hospital, and I expect to be okay, and if I'm not, they've let me down.

Bill 28:38

But no, that's when strike recovery becomes your responsibility. And you need to be the person who says, Thanks for getting me to this point. Now, what do I have to do? Who do I have to recruit? How am I going to go about getting to the next milestone and then the one after that?

Bill 28:57

And it's just a really lovely way for you guys, your team and clinical researchers to get to this point of helping people get stronger after stroke by focusing on things that we all do as humans is we just have these things that we've always done, and now we're just applying it in a new way to recovery from an ailment.

Repetitive practice - Peter G. Levine



Bill 29:27

Yeah, I think what you're headed towards, and it's where you should head is simplicity. Why do we have to make it so complicated? If we know that repetitive practice makes you better at something, of course, it's going to happen in basketball, and of course, it's going to happen with stroke recovery.

Peter 29:54

And I think that that's like been a great asset that I've had that I've worked with really smart people. And really smart people have helped me come to the conclusion that it's the simple stuff, the stuff that we've been doing for 250,000 years as human beings to be really highly skilled at different things.

Peter 30:14

So the other thing is, the other point that you made is that discharge from therapy is not the beginning of the end, it's the end of the beginning. What they do is kind of a little sneaky, though clinicians. So here's what happens. After a stroke, you have this area that's dead. And then there's this area that surrounds it, it's called the Penumbra.

Peter 30:38

And it heals, and as it heals, there's originally some swelling around it. And that makes the neurons not work very well. They're still alive, but they're not working. They're said to be stunned. It's called cortical shock, there's a technical term for it. But as that all the swelling goes down over the first three months, usually, those neurons start to come back.

Peter 31:04

And as they come back, the person makes quite, the incline in ability gets very intense, they get really good. But at some point, that all that Penumbra is back online, and they naturally and it's a it's an occurrence, it happens to everybody, they plateau.

Intro 31:24

If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind. Like how long will it take to recover? Will I actually recover? What things should I avoid in case I make matters worse, doctors will explain things, but obviously, you've never had a stroke before, you probably don't know what questions to ask.

Intro 31:48

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 the seven questions to ask your doctor about your stroke.

Intro 32:07

These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke, they'll not only help you better understand your condition, they'll help you take a more active role in your recovery. head to the website. Now, recoveryafterstroke.com and download the guide. It's free.

Bill 32:26

That plateau. I don't know how it is in Australia, but in the United States. What they do is they discharge you when you plateau. The thinking is, if you're not getting any better, why are we spending money on you? Why are we spending time on you?

Peter 32:41

The thing is, though, that they discharge them. And then the person usually goes home and gets worse. Why? Because they're sitting around not doing their exercises the way they should. They're kind of stunned by the whole process. Oh, no, I've been discharged. I guess that's all I'll get. She told me that I'm done recovering, I've plateaued.

Peter 33:03

And she's the expert. So now what am I supposed to do? So they go home, they relax, and they actually get worse, there's a declination. So at that point, yes, it's not the beginning of the end, it's the end of the beginning, the gains get very much harder to get. There's no doubt about it. You don't have this easy ride of the brain coming back online. Now you got to start to work the same way. As you pointed out, Michael Jordan worked. Did you see the series about the Bulls that was on Netflix?

Bill 33:40

I haven't seen it yet. But yeah, I do know the one.

Bill 33:42

Yeah. So I mean, like, he went through this process of okay, now he couldn't jump through the roof anymore. So he had to lean on this jump shot. And then he realized that he had to be more of a team player, there was all these things he had to go through to grow.

Peter 33:58

Yes, he was a brilliant basketball player that's discharged. Okay he was already brilliant when he got out of college. Now, was he going to do the hard work that takes him just a little bit more, and then stroke that just a little bit more of the difference between, you know, holding on to relationships, getting back to work, getting back to school, getting back to a sport, it's those little things at the end that they do themselves that are super important.

Peter 34:27

I happen to be lucky in that a lot of our research had to do with people that were chronic, that was after their plateau. See, if you do a study, during the part in which the brain is coming back online. How do you know if it's something you did? Or if it's just the brain coming back online?

Peter 34:45

The way we typically do that is we have a control group. And then we have an experimental group, and we see who gets better. Now if it was something we did, then the experimental group will get a little bit better than the control group. But a lot of our studies were in chronic people. So they It already plateaued, they were not supposed to get better.

Peter 35:03

Clinicians were convinced they wouldn't get better. And I'm not just talking about therapists, I'm talking about physiatrists, I'm talking about neurologists, they all kind of believe for a very long time, you couldn't get better after that three months or six months, or as your friend says, seven months.

Peter 35:20

Now, we know that that's not true, the brain is incredibly plastic, we don't even know what the parameters are. So now you got to chip away. And just like a really high level athlete, or really high level musicians, you're not having these great, I wasn't walking, now I am walking, my arm wasn't working, now what is working, it's not going to be these big fancy things, it's going to be these little things.

Peter 35:41

And often stroke survivors are not really good at measurement. Because they're not good at measurement. They can't tell they're getting better. One thing I would suggest that any stroke survivor does is videotape yourself, if it's going to come down to a nuanced change, then videotape yourself over months and see if you're honest with yourself, because you may be getting better, but you don't see it.

Peter 36:05

Maybe other people do, who haven't seen you for three months. But if you have a videotape, if it's a speech deficit, record your voice, whatever it takes to show that yes, you are getting better, or you're not. Because if you're not getting better, you got to change something up, you got to get got to do something else.

Bill 36:23

Yeah, I completely agree with that a lot of the people that I speak to will tell me, they're not doing better, or things are worse or not as good or whatever. And one might be having a conversation with them. And three months earlier, I wasn't able to have a full on conversation with them or I wasn't able to talk with him for beyond 20 minutes and now I'm talking to them for 30 or 40 minutes.

Bill 36:48

And there's all these little bits and pieces that they missed, because they're focusing on what they can't do, rather than what they can do. And if they simply shift their focus on what I can do, and do more of that, they will be able to get a better outcome. And they'll be able to feel better about themselves, because they're constantly reinforcing oh, my gosh, I did that, and wow, I did that, and

now I've done that, and now I've done this.

Bill 37:17

And if you go back and reflect on all the things that you've done, those things that will far outweigh all the things that you haven't done, because if you can't walk, because you have a particular problem with one of your legs, and three months down the track, you still can walk, nothing's really changed. It's just I'm not walking, and I haven't walked.

Bill 37:36

But if your leg, also, at the beginning of that three months, didn't have feeling and now it does. And if you like also at that three months, at the beginning of that three months, couldn't move your toes. And now you can it kind of is irrelevant, that you can't walk it, what's relevant is that you have feeling back on your toes are working.

Bill 37:58

And now you're closer to being able to use that leg when you were three months ago. And we need to focus on those things, we need to focus on the things that are going to give us the boost.

Bill 38:10

And if you have somebody that's trusted, that loves you, that's caring for you, that's helping you a friend, that's telling you those things pay attention, they're not just saying it because they want to make you feel better, they're saying it to you because maybe you're not paying attention, and they want you to have an awareness of it.

Bill 38:30

And they want you to focus on what you have been able to achieve rather than what you can't. And I think that we're also as humans, even before stroke, our own biggest critic and our own worst enemy. And stroke just makes things a little bit more detailed or complicated or difficult when it comes to exacerbating or highlighting our weaknesses or our problems or our challenges.

Bill 39:00

And if we let it, it could really take that conversation of I'm not good enough or I'm not able and it could really spiral out of control. It's really important that what we're doing is using our way of being and thinking in the opposite way and using it against the negative side, then trying to turn it and convert it into the positive side. It's the same amount of energy that we use to have negative thoughts.

Bill 39:29

We could just switch it and have positive thoughts. It's the same amount of time and effort and in fact, it's less emotionally draining so therefore it's going to take less energy to have a conversation that's positive and going to make you feel better.

Safe in negativity

Bill 39:45

So why do you think we feel safe in the negative because I find this in my own life. It's just easy to go I can't accomplish that, It's too hard, I can't see the force through the woods kind of deal. What do you think? I wonder if it's, it's a safety thing, it's a safety valve, I'll just go to where I'm safe, but negative, rather than this uncharted territory that has potential.

Bill 40:12

I think because, and I'll speak personally, I can't speak for everybody. But for me, I think it was growing up when I was probably starting to first interact with children in a big way, which was at a school, you know, perhaps I listened to children highlighting my differences or highlighting the things that they weren't aware of.

Bill 40:35

And I picked up a little bit of information from them once and then it happened three weeks later, and I took that on board. And that became the theme of what I continue to hear. And then sometimes, my older brother who wanted to exert his authority, as three years older than me, you know he said, you can't do that, or you're not going to do that, I'm not going to let you do that, or whatever, you know, just being a child.

Bill 40:59

And that grew and grew, and became this thing that I didn't realize was happening to me, because it was happening every day. It's like, it just creeps up on you, it just happens slowly, but surely. And we don't have enough self awareness or somebody hasn't jolted us into showing you how those incremental steps have shaped your life.

Bill 41:24

And now you're an adult, and you haven't reflected on that ever. And you've never had somebody coach you or guide you or support you. And reverse some of that, I'll call it a spell, reverse some of that spell that was placed on you over those years. And that's what I feel like coaching does, people eventually get to the point where they get fed up with feeling like they can't, or they won't or they shouldn't or they're not up for it.

Bill 41:54

And then a coach will say, yeah, you can, yes, we could. And yes, we will overcome it and watch on the other side of that fear is relief and growth, and a new experience and new emotions and all these amazing new things. And I know it's unfamiliar, so because you're not certain or sure about what's on that other side, you'd rather stay with the devil, you know, than the devil you don't.

Bill 42:20

And why don't we put that devil that we do know, why don't we put them on the back foot for once and send them elsewhere and go to somewhere else where there might be an angel on that other side, not a devil. And then life changes and switches. And I've noticed that for myself that I was also going to the wrong people Peter, for advice.

Bill 42:45

And as a 25, 26 year old, I would go to people that were not business inclined, and ask them for business advice. Now, it was because they were older than me or the people that I lived with, or that were around more often than others. So of course, when I didn't know who to seek out, I would seek out people that were unqualified to answer.

Bill 43:06

And I would get their advice. And then I wouldn't get the advice I wanted, I'd be frustrated and upset with them, I would blame them for telling me that I wasn't capable of doing something because they were projecting their experience onto me. And I had no conscious awareness of how that interaction was my fault, I was the one that was creating that by just going to the wrong place.

Bill 43:31

And when I finally got sick and tired of getting the wrong feedback, I started to seek out people who had done what I wanted to do. And asked them to tell me what I needed to do to get there. And that changed my world. And that's why as my podcast suggests, recovery after stroke, I've taken this position nine years after my experience first started to say I am where you want to be.

Bill 44:05

And if you ask me, I will tell you how to get there. And if you're afraid I will hold your hand. And if nobody has ever told you that it's okay to be afraid, but do what you have to do anyway, I'll be the guy. And if you want to ask a million questions, just ask. So I'm now offering this part of me in a way that I was hoping that I would find in another stroke survivor.

Bill 44:35

And I must say there wasn't anyone specifically that I could reach out to when I was in my acute phase to give me hope and to give me support and guidance and I sought out other people in other parts of the world like you who are researchers like Dr. Michael Merzenich. You know, who's considered the godfather of neuroplasticity, you know?

Bill 44:55 Yes, he is. Have you interviewed him?

Bill 44:59

I interviewed him years ago and I re-released the interview for Episode 108. And we spoke about rewiring the brain and we spoke about all those things because I didn't know who else to turn to. And I figured who best than the Peter Levines of the world and the Michael Merzenichs, of the world to hold my hand and tell me that we'll be okay I'm going forward.

Bill 45:22

Don't put me in the same league as him. You know what he created? He created the cochlear implant. So, it was through that research that he was one of the first to measure neuroplastic change the guy's a Nobel Prize winner just waiting to happen.

Bill 45:38

We spoke about the cochlear implant on that episode. And in fact, this year in Australia was the anniversary of the invention of the cochlear implant because the team that actually took it to market was an Australian team of scientists who was also working in conjunction with, and collaborating with Dr. Michael Merzenich and his team in the States.

Bill 46:02

I'm pretty sure there was another team in the UK, who all collaborated to come up with the data the proof that neuroplasticity actually occurs. And Dr. Michael says in the interview, he says that they created a device. And they had no idea that it was the brain that made the device able to work.

Bill 46:26

Because if the brain wasn't plastic and wasn't able to adjust and learn to take information in from this electronic device to create a new path towards hearing, then the device would be completely useless. So it's a fascinating conversation. fascinating topic.

Bill 46:45

Anyone who hasn't had the opportunity to go back and listen to the episode with Dr. Michael Merzenich needs to do that, it's episode 108. He's an amazingly generous man. And his work is changing the lives of people that have neurological deficits in all aspects of life.

Bill 47:08

That's right, posit science. I mean, it's dyslexia. He thinks that dyslexia is actually an auditory issue. And then if you throw quick, you know, the whole system, but posit science, definitely, I think, first of all, I should point out to you, Bill, that, I think would be a good idea and I don't know if you have this, but we should stick an ad on my blog for your coaching.

Peter 47:35

Because I think, you know, people may not know that that exists. They may know life coaches exist. But stroke recovery life coaches, that's a whole different thing. So let's talk about that. Then the other thing is, isn't it interesting how the resilience that you develop, because something that happened at school, and your brother and all the things that led up to the stroke are the same things that you brought to bear?

Peter 48:01

Isn't it interesting that, you know, when we talk about what works seems to work

in clinical research is the simple stuff that we've been doing for hundreds of thousands of years as human beings anyway, we end up in the same place, it's all the same thing that works for any kind of challenge in your life certainly works word, this monumental challenge of recovering from stroke.

Bill 48:25

It does. And you know, what's interesting is that, you know, stroke creates anxiety, and it creates depression. But if you get a stroke survivor, and you ask them about their anxiety and the depression after the stroke, they're likely to be people who experience stroke and who experience anxiety and depression before stroke.

Bill 48:42

So there's never been a bigger reason to get to the bottom of what is causing your anxiety of depression. Now that stroke has occurred and forget about stroke recovery, if you're experiencing anxiety, and depression, and you can get to the bottom of that your stroke recovery is going to take a turn for the better on its own.

Bill 49:03

And we've got to overcome all these little things that we've never overcome in life, and we've never dealt with in life. Because if we get those out of the way, then we can really put all our resources and energy into stroke recovery.

Bill 49:20

And we can harness the information that you and your team and the thousands of other researchers in the world provide, which is proof that we can positively impact our own recovery. And I think clinical researchers, people that haven't had a stroke that are working in that field, are the most amazing people on the planet.

Bill 49:46

And I love them more than anybody. Because if you were a stroke survivor and you thought you're alone, you are completely wrong, because there's thousands of people like Peter working for a lifetime. To help people they've never met before and don't know, what do you say to that Peter?

Bill 50:07

You know, I do a lot of clinical education talks. So I go around the country when I'm lucky, I go overseas. And I've done hundreds of these talks. These are boring

six-hour talks to occupational therapists. And do you guys call them physical therapists or physiotherapists?

Bill 50:25 Physiotherapists? And also Yeah, we have occupational therapists as well.

Bill 50:29

Right, so a physiotherapist. So that's who I do most of my talks to. My wife is actually what we call a physical therapist, a physiotherapist. And it was interesting. She came to one of my talks, and it was probably the scariest experience I ever had. She was also a clinical instructor of mine in school.

Clinical Education Talks



Peter 50:49

So it was interesting. But here's what happens. You know, during a six-hour talk, you have a couple breaks, and somebody will come up to me a therapist. And they'll say, Can I ask you a question? I go, sure, and they say, I got this guy, they always had it start out with that. I'm working with this guy. I call them I got this guy questions.

Peter 51:15

Okay, tell me about the guy. Well, he has so much spasticity. I don't know how to get the hand open. And then when he goes to walk, he lurches, and he has terrible balance, and he's falling over. And he's very impulsive, and I don't know what to do. And I look at this person, this therapist, and there's tears in their eyes.

Peter 51:37

I'm like, is this your dad? Are we talking about your dad here? Is this well, family members? Is somebody is this a good friend, because this is insane that you are this emotionally invested in this, my daughter is going into this pre-speech therapy, she's 20 years old.

Peter 51:55

You know, my son's going into athletic training, which is related. My wife's a PT. I'm on the PT side of things. It's, it's an occupational hazard. Look, here's what I'll say, you will not do well, in the business of rehab. If you don't give a crap, you will get eaten up, you'll get chewed out by the patients themselves, who will sense that you don't give a crap.

Peter 52:22

And they won't give a crap about you and I've seen people try to do it. But they all end up very unhappy. They just got in the wrong business. But most of them, I agree with you there. They do pretty monumental things. There have been mistakes that clinicians and rehab have made, I think, discharging people on upon plateau.

Peter 52:45

I think in the United States. The average length of stay in the hospital is 5.5 days after a stroke. In most of Europe, it's about 20 days in the Netherlands, it's like a month. That's a mistake to discharge somebody from the hospital to go back home or to go into a nursing facility or work or a rehab hospital. It's a it's cruel behavior, to discharge them to a totally new environment that early after the stroke.

Peter 53:19

Other mistakes that clinicians have made, but I agree with you their heart is in the right place. And I think it's up to people like me to just harness it in a way that allows them to leverage the great neuroscience that we have. Michael Merzenich's work. I'm sure I'm pronouncing his name wrong. Alvaro Pascall Leoni, Edward Tabb, all these guys that have done the great neuroscience on this stuff, and help therapists leverage it. If they can just get that in there. I think they'll do even better than they already have. And they're already doing a good job. You're right.

Bill 53:54

They're doing a great job I feel so supported and so grateful for the fact that in Australia, we have the National Stroke Foundation, who supports research and funds, some programs to support stroke survivors. And associated with them in a big way is the Florey Institute, which is a brain research institute.

Bill 54:21

You know, the Florey Institute has offices, I'm sure it's all over Australia. I've been to their lectures in Melbourne where Michael Merzenich first spoke and I first heard about him and learned about him. And then stroke survivors, perhaps aren't that curious about what's out there and what they can learn themselves with regards to the cutting-edge research that's being done in the new findings that we're discovering and the breakthroughs that are happening in brain health and recovery.

Bill 54:57

And previously, it was this strange world that non-academic people like me wouldn't go to I wouldn't go there. Because I wasn't an academic. I didn't know anything about academics, I didn't know how to behave, or act in those scenes. Not that I needed to actually all I needed to do was turn up. But I had this idea in my head that I shouldn't be hanging around there.

Bill 55:20

And when I finally went there, I just realized, Oh, really passionate, cool, amazing people helping other people. And now what the beauty of it is, is now I get to take people like yourself, out of the lab, into my podcast into the ears of around 4000 people a month who download my podcast.

Bill 55:38

And there you go, we've bridged one of those challenges that we had, which was taking new information and new ideas to people. And I really appreciate the fact that you're so keen to, not only because isn't that the most important because not only do you need to learn these things, about how to help, you need to tell people that you've learned them and that they exist, and how they can apply them to their daily life.

Bill 56:09

That's the flip side. And we struggle a lot with that in our lab, we would have long discussions, big, long arc discussions, what we're doing this great work, but we're publishing in a peer-reviewed journal article that probably clinicians won't even read, let alone people who have had a stroke.

How do we get to these people have had a stroke? And my answer was, let's do a lot more talks. Let's write a book, I wrote a lot of articles, I got a blog, I do what I can. And I'm actually going to follow your lead. And me and an occupational therapist here in the states are going to start a podcast specifically about brain injury and what therapists can do to sort of stay up to date was some of this stuff.

Peter 56:54

But I agree with you, I mean, there's nothing, a really good researcher should be able to explain their work in a way that makes sense to everyone. Same with therapists, same with life coaches, if you can't make it simple, it's it doesn't help anybody.

Bill 57:11

Let's talk a little bit about as we come to the end, before we wrap up, let's talk a little bit about the book Stronger After Stroke. It's the third edition. And its subtitle is your roadmap to recovery. Tell me a little bit about the book.

Bill 57:27

So I was writing articles in a trade magazine, physical therapy trade magazine, and I had a monthly article, it's called from the lab. I didn't name it, somebody else named it don't blame me, well I worked in a lab, so it made sense to them. So one of the articles I wrote was 10 things that stroke survivors can do to drive their own brain towards recovery.

Peter 57:53

And, then I thought, well, you know, I'm doing these talks to clinicians, I wonder if I can come up with 101 things, you know, how they write, like, 101 things you can do to fix your home or 101 things you can do to make your self happier, whatever it is, so but I got, and I started writing this book, and this was in 2004, or so.

Peter 58:14

And I got to about 40. And it was hard like, I don't have anything else. There's like, I'm looking at all the research, not just from our lab, but from other labs, and I just couldn't find more than 40 things. So that's about the time I changed the name to stronger after stroke.

Peter 58:32

I originally wrote it for clinicians to sell in my talks, you know, I would go to these

hospitals and do talks. And they were like, what do you have a book, you know, you're supposed to be selling a book, right? Yeah. So I self published it. I went to Kinko's, which is our local, you know, the place that will, you know, bind a bunch of papers into a book.

Peter 58:32

And, I sold it, and it did well, and then wrote a couple of emails to some publishers and, and one of them was interested, they said, We'd like your book, we'd like the idea. Here's what we want you to do. rewrite the whole book, because right now, you've written it for clinicians.

Peter 58:32

And it's a little technical for us, we need to sell to stroke survivors. In the United States alone, there's about 800,000 strokes per year. That's the market we want to hit. And so I spent about three months, just shortening the sentences, making everything simple. And bringing it down into a simple format, which is, how do you do it? How do you set it up?

Peter 58:32

And then what are the precautions and then just going through mirror therapy, constraint news therapy, imagery, mental practice, all these other paradigms that we had used in that we had done research on and others had done as well. And so it was really just an outcropping of trying to make things simple and try to bring the research to the people. And a lot of clinicians read it as well, because they want simple to everybody wants simplicity.

Keeping track of progress

Bill 1:00:07

Yeah, it's complicated is too hard for most people, let alone stroke survivors who challenging the body to start to relearn how to do things that used to do without any thought whatsoever. And I found that too much information or too muchcomplicated information was just, it would just, you know, glaze my eyes over and that was it.

Bill 1:00:31

No more, information about that was going to go in my ear didn't matter how long was spent looking at the page or listening to somebody talk about it. So it's

definitely going back to the basics, it's definitely going back to those first things that we did when we were just learning how to get up on our feet, learning how to walk again, learning how to do all those things from babies, it's just really going back to the bare bones, bare basics, and then just improving on the things that you're already good at.

Bill 1:01:07

And doing those even better, and I suppose being aware of what you're not go that. And then just focusing and then just noticing how that changes through that advice that you gave, which was record yourself talking, record yourself walking, and just look back on it regularly to make sure that you're noticing the improvements.

Bill 1:01:37

Yeah, yeah, I think you made a good point in there. It was like in the third sentence, work on stuff that you're bad at. Because the stuff that you're good at, you can do. And you know, any musician, a guitar player will pick up a guitar and they always first thing they play is their favorite riff.

Peter 1:01:56

But it's the challenge outside of that stuff that you're already do well, that's where the real pot of gold is. And that's where measuring videotaping, audio recording all that stuff can be really helpful to give you a sense that you're getting better, you may not see it day to day, but month to month, there may be some big changes in there.

Bill 1:02:19

But I really appreciate you reaching out and asking me to be a guest. I really love it. When people do that. It excites me that actually people are interested in being on my podcast. But more importantly, I'm glad that you did that. Because the work that you're doing is really important.

Bill 1:02:38

And people need to hear about it, and people need to know about it. So if anyone wanted to find out a little bit more about you, I will have all the links in the show notes so people can find you easily. But just remind us where can people find more about you and your book? Where would they go online?

Bill 1:02:57

So probably the best portal to everything is the blog and you get on Google at google.com incase can't find it. And you put in Google you put in Stronger After Stroke blog, you get those four words in there. I promise it'll be the first hit. The book is called Stronger After Stroke. There's a link to the book there. Although I guess it's a link to amazon.com not your guys or wherever you guys buy stuff. You know, it's the middle of the summer for you, isn't it?

Bill 1:03:32

Well, it should be but we haven't really had much of summer we're experiencing the the La Nina, which is supposed to be a colder version of summer. So I can't say that we've been to the beach more than about three or four times this year. We're normally we might go 15 or 20 times so it's been a very mild and not summery summer.

Bill 1:04:02

Well, we'll look forward to that going into summer because we're having the polar vortex right now we're very cold air from the Antarctic from Canada is just sweeping down. We've had crazy weather events. Actually, I forgot what my point was. Anyway, so the book is easy to find it just goes stronger after stroke you're gonna find me no problem. And my my email address is strongerafterstroke@yahoo.com and feel free to ask me any questions that you have and I'd be glad to do my best to answer them.

Bill 1:04:33 Thanks for being on the podcast.

Bill 1:04:35 My pleasure.

Intro 1:04:41

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Intro 1:05:24

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Intro 1:05:45

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Intro 1:05:58

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Intro 1:06:15

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