

Exercise And Stroke Recovery | Dr. Heidi Jansen

The Role of Exercise in Stroke Recovery: A Comprehensive Guide

Exercise plays a crucial role in stroke recovery, aiding in physical, cognitive, and emotional rehabilitation. When it comes to regaining independence and improving quality of life after a stroke, incorporating exercise into a rehabilitation program is key. In this comprehensive guide, we will explore the various ways exercise can support stroke recovery and provide practical tips on how to get started.

Physical exercise helps strengthen muscles, improves balance and coordination, and enhances mobility. It can also help prevent muscle atrophy and reduce the risk of secondary complications such as blood clots and infections. Cognitive exercises, on the other hand, promote brain plasticity, enhance memory and concentration, and improve overall cognitive function. Additionally, exercise has been shown to have positive effects on emotional well-being by reducing post-stroke depression and anxiety.

Whether you are a stroke survivor, a family member, or a healthcare professional, this guide will provide you with valuable insights and practical advice on how to incorporate exercise into a stroke recovery plan. Discover the transformative power of exercise and take a step towards a healthier and more fulfilling life after a stroke.

Understanding the role of exercise in stroke recovery

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exercise can support stroke recovery and provide practical tips on how to get started.

Benefits of exercise for stroke survivors

Physical exercise helps strengthen muscles, improves balance and coordination, and enhances mobility. It can also help prevent muscle atrophy and reduce the risk of secondary complications such as blood clots and infections. Additionally, exercise promotes cardiovascular health, which is essential for stroke survivors who may have experienced damage to their heart and blood vessels.

Cognitive exercises, on the other hand, promote brain plasticity, enhance memory and concentration, and improve overall cognitive function. Stroke survivors often experience cognitive impairments, such as difficulty with memory, attention, and problem-solving. Incorporating cognitive exercises into the rehabilitation program can help address these challenges and improve the individual's cognitive abilities.

Furthermore, exercise has been shown to have positive effects on emotional well-being by reducing post-stroke depression and anxiety. The emotional impact of stroke can be significant, as survivors often face changes in their physical abilities and lifestyle. Engaging in regular exercise not only enhances physical and cognitive function but also boosts mood and overall mental well-being.

Types of exercises for stroke recovery

Exercise offers numerous benefits for stroke survivors, both physically and mentally. First and foremost, it helps to improve overall physical function and mobility. Through targeted exercises, stroke survivors can regain strength, improve flexibility, and enhance their ability to perform daily activities independently. Regular exercise also aids in balance and coordination, reducing the risk of falls and improving safety.

In addition to the physical benefits, exercise plays a crucial role in cognitive rehabilitation. Cognitive exercises, such as memory games, problem-solving activities, and attention training exercises, help to stimulate the brain and improve cognitive function. This can lead to enhanced memory, attention, and decision-making abilities, ultimately improving the individual's overall cognitive

performance.

Exercise has also been shown to have a positive impact on mental well-being. Engaging in physical activity releases endorphins, which are natural mood boosters, and can help alleviate symptoms of depression and anxiety. Additionally, exercise provides an opportunity for social interaction, which can combat feelings of isolation and improve overall emotional well-being.

Creating an exercise plan for stroke survivors

Various types of exercises can benefit stroke survivors. It's important to consider the individual's abilities, preferences, and any specific limitations or precautions recommended by their healthcare team. Here are some types of exercises commonly recommended for stroke recovery:

1. **Strength Training:** Strengthening exercises focus on building muscle strength and improving overall physical function. This can include exercises using resistance bands, weights, or bodyweight exercises. Starting with low resistance and gradually increasing as strength improves is recommended.
2. **Aerobic Exercise:** Aerobic exercises, such as walking, swimming, or cycling, help improve cardiovascular fitness and endurance. These exercises can be tailored to the individual's abilities, and it's essential to start slowly and gradually increase the intensity and duration.
3. **Balance and Coordination Exercises:** Balance and coordination exercises help improve stability and reduce the risk of falls. This can include exercises such as standing on one leg, heel-to-toe walking, or balance board exercises.
4. **Flexibility Exercises:** Stretching exercises help improve flexibility and range of motion. These exercises can include gentle stretches of major muscle groups and joints, such as the neck, shoulders, arms, and legs.
5. **Cognitive Exercises:** Cognitive exercises focus on stimulating the brain and improving cognitive function. This can include memory games, puzzles, reading, or engaging in activities that require problem-solving and critical thinking.

Safety considerations when exercising after a stroke

When creating an exercise plan for stroke survivors, it's crucial to consider their individual needs, abilities, and goals. Here are some key steps to follow when developing an exercise plan:

1. **Consult with Healthcare Professionals:** Before starting any exercise program, it's essential to consult with the individual's healthcare team, including their physician, physical therapist, or occupational therapist. They can provide valuable insights and recommendations based on the individual's specific condition and needs.
2. **Set Realistic Goals:** Establishing realistic and achievable goals is crucial for stroke survivors. These goals can be related to physical function, cognitive abilities, or emotional well-being. Breaking down larger goals into smaller, manageable milestones can help keep motivation high.
3. **Develop a Balanced Routine:** A well-rounded exercise routine should include a combination of strength training, aerobic exercise, balance and coordination exercises, flexibility exercises, and cognitive exercises. This ensures that all aspects of recovery are addressed.
4. **Start Slowly: It's important to start with exercises that are appropriate for the individual's current abilities and gradually progress as strength and endurance improve. Starting slowly helps prevent injuries and allows the body to adapt to new demands.**
5. **Include Rest and Recovery: Rest and recovery are essential components of any exercise program. It's important to listen to the body and allow for adequate rest periods to prevent overexertion and promote optimal recovery.**

Overcoming barriers to exercise during stroke recovery

While exercise is beneficial for stroke recovery, it's essential to prioritize safety. Here are some important safety considerations to keep in mind when exercising after a stroke:

1. **Consult with Healthcare Professionals:** As mentioned earlier, consulting with healthcare professionals is crucial to ensure exercises are safe and appropriate for the individual's condition. They can guide you on any precautions or modifications that may be necessary.
2. **Warm-Up and Cool-Down:** Always start each exercise session with a proper warm-up to prepare the body for physical activity and reduce the risk of injury. Similarly, end each session with a cool-down to gradually bring the heart rate back to its resting state.
3. **Use Proper Form and Technique:** Proper form and technique are essential to maximize the benefits of exercises and minimize the risk of injury. If unsure about the correct form, it's recommended to seek guidance from a qualified professional, such as a physical therapist.
4. **Monitor Heart Rate and Blood Pressure:** It's important to monitor heart rate and blood pressure during exercise, especially for individuals with cardiovascular concerns. Staying within safe ranges ensures that the exercise is effective and does not place excessive stress on the body.
5. **Stay Hydrated:** Proper hydration is important during exercise to prevent dehydration and maintain overall well-being. Ensure that the individual drink an adequate amount of water before, during, and after exercise.
6. **Listen to the Body:** It's essential to listen to the body and pay attention to any warning signs or discomfort during exercise. If experiencing severe pain, dizziness, shortness of breath, or any other concerning symptoms, it's important to stop exercising and seek medical attention.

Incorporating other therapies with exercise for optimal recovery

Despite the numerous benefits of exercise, stroke survivors may face various barriers that make it challenging to engage in regular physical activity. Here are some common barriers and strategies to overcome them.

1. **Physical Limitations:** Physical limitations, such as weakness, spasticity, or difficulty with coordination, can make exercise challenging. Working with a physical therapist or exercise specialist who specializes in stroke rehabilitation can help develop tailored exercises and modifications to accommodate these limitations.

2. **Lack of Motivation:** Lack of motivation can be a significant barrier to exercise. Setting realistic goals, finding enjoyable activities, and seeking support from family, friends, or support groups can help boost motivation.
3. **Time Constraints:** Balancing rehabilitation, work, and other responsibilities can make it challenging to find time for exercise. Prioritizing exercise by scheduling specific times and making it a part of the daily routine can help overcome this barrier.
4. **Financial Constraints:** Access to exercise facilities or specialized equipment may be limited due to financial constraints. Exploring low-cost or free options, such as walking outdoors, using household items for resistance training, or accessing community resources, can help overcome this barrier.
5. **Fear of Injury:** Fear of reinjury or exacerbating existing physical limitations can be a significant barrier to exercise. Working with a healthcare professional to develop a safe and appropriate exercise plan, and starting with low-intensity exercises can help alleviate these concerns.

Tracking progress and adjusting exercise routines

While exercise is a vital component of stroke recovery, it's important to recognize that it works synergistically with other therapies to optimize recovery. Here are some therapies that can complement exercise in the rehabilitation process.

1. **Physical Therapy:** Physical therapy focuses on improving physical function and mobility through targeted exercises, manual therapy, and other techniques. Incorporating physical therapy alongside exercise can help maximize recovery and address specific physical limitations.
2. **Occupational Therapy:** Occupational therapy focuses on improving the individual's ability to perform daily activities independently. This can include exercises that target fine motor skills, coordination, and adaptive techniques to overcome challenges in daily life.
3. **Speech Therapy:** For stroke survivors who experience speech and language difficulties, speech therapy can be highly beneficial. Speech therapy improves communication skills, clarity, and swallowing function.

4. **Psychological Therapy:** Psychological therapy, such as counseling or cognitive-behavioral therapy, can provide valuable support for stroke survivors dealing with emotional challenges, such as depression, anxiety, or adjustment difficulties. These therapies can work in tandem with exercise to promote overall well-being.

Conclusion: The power of exercise in stroke recovery

To ensure continued progress and maximize the benefits of exercise, it's important to track progress and adjust exercise routines accordingly. Here are some strategies for tracking progress and making necessary adjustments:

1. **Keep an Exercise Journal:** Maintaining an exercise journal can help track exercises performed, intensity, duration, and any noticeable changes or improvements. This provides a visual record of progress and helps identify areas that may require adjustment.
2. **Regularly Assess Physical Function:** Regularly assessing physical function, such as strength, balance, and mobility, can provide insights into progress and areas that may need additional focus. This can be done through functional tests or with the guidance of a healthcare professional.
3. **Review Goals and Make Adjustments:** Periodically reviewing goals and making necessary adjustments is essential for continued progress. As the individual's abilities improve, goals can be updated to reflect new milestones or challenges.
4. **Seek Professional Guidance:** If progress stalls or difficulties arise, seeking guidance from healthcare professionals, such as a physical therapist or exercise specialist, can provide valuable insights and recommendations for adjusting the exercise routine.

The Interview

Dr. Heidi Jansen is exploring how to get the best results from exercise during stroke recovery.

Esteem Stroke Instagram

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Dr. Heidi Jansen 0:00

When we look at animals that recover from stroke in an environment where they have access to greater opportunities to combine physical, cognitive, and social activities, it promotes brain plasticity and improves their motor function. And there's some indication that it helps their memory and learning. So based on the science, we then say, well, what does this look like?

Dr. Heidi Jansen 0:21

For want of a better word in a human model? It's got to have those three elements and they're like, well, we don't want to exercise for too long. Survivors. Yeah, well, because people will get tired. Yeah, I hear that.

Dr. Heidi Jansen 0:34

But as a physio I sit there and say, Okay, well, it's going to be a quick 30-minute set of tasks 30 minutes if we want to get that actual element in, so they do 30 minutes of exercise, and then they break for tea and coffee and have some yummy food and share their stories.

Intro 0:57

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

Bill Gasiamis 1:10

Hello, everybody, welcome back to the podcast. My book, The Unexpected Way That a Stroke Became the Best Thing That Happened is now available for purchase on Amazon. Just search my name on your local Amazon Bill Gasiamis, or follow the links in the YouTube description.

Introduction Dr. Heidi Jansen



Bill Gasiamis 1:28

And in the show notes for this episode. If you are an Aussie and follow the Australian link, the book will be shipped by me personally, which means I'll even be able to sign it for you with a special message. Now, this is episode 283.

Bill Gasiamis 1:45

And my guest today is Dr. Heidi Jansen, who is an accomplished physiotherapist and dedicated researcher specializing in stroke recovery and rehabilitation. Her passion lies in ensuring stroke survivors receive effective rehabilitation and post-stroke care aiming to optimize their recovery. Her research primarily focused on environmental enrichment and secondary prevention through regular physical activity. Dr. Heidi Jansen, welcome to the podcast.

Dr. Heidi Jansen 2:16

Oh, thanks for having me, Bill.

Bill Gasiamis 2:18

My pleasure. Thank you for being here. Tell me a little bit about yourself. Who you are in your professional role, where do you work, and what do you do?

Dr. Heidi Jansen 2:28

I'm a physiotherapist that's based in Newcastle, New South Wales. And I've been a physiotherapist for over 21 years now of which most of that has been spent working in the stroke recovery space along all aspects from acute through to my current role, which is working with people living with stroke who are back at

home, and learning how to live well with changes that may have occurred after stroke.

Dr. Heidi Jansen 2:59

So I work for Hunter New England Health in the community stroke team. That's the team that does that. We run group programs that involve things like supporting self-management and secondary stroke prevention, mood changes, fatigue, and communication changes. And my other role that I've been involved in probably for 15 years or so, is as a stroke researcher.

Dr. Heidi Jansen 3:29

So I have a special interest in the use of environmental enrichment to promote stroke recovery. I also have a research interest in secondary prevention interventions. I'm involved in working with an Aboriginal community on Gomeroi in the Loralay, which lands up in Tamworth, New South Wales, and I'm also developing an avatar to support self-determined stroke recovery.

Dr. Heidi Jansen 4:00

So that's a little bit about me, I've got a bit going on. But as you would it sounds like I like to be busy. And I'm very interested. I don't have any personal connection to stroke in terms of having someone in my family or myself who has had a stroke.

Dr. Heidi Jansen 4:17

But I'm very passionate about ensuring that everybody that has a life-changing event, we just stroke most definitely years. They all have equitable access to the best support and evidence-based care to help them learn to live again.

Dedicating a career to stroke research and rehabilitation

Bill Gasiamis 4:37

How did you get interested in stroke 21 years ago when you were fairly new to the research world or university life and all of that? What is it that sort of says, I think I'm gonna do the next 21 years in this space.

Dr. Heidi Jansen 4:54

I fell into a clinical role accidentally so there was a new stroke unit that was being

built, so to speak, and a new service was being developed in a smaller hospital within the area of Newcastle, not the main tertiary hospital, another little hub hospital.

Dr. Heidi Jansen 5:16

And yeah, I was the physiotherapist involved in and working with a multidisciplinary team to set up these acute stroke units, which transitioned into a stroke rehab unit. So that continuation of care. So you start rehab, as soon as you're medically stable, it was a cute stripe. So yeah, since then, I've just moved about in different stroke specialties.

Bill Gasiamis 5:45

Yeah, it's cool. I asked that question to most people who are researchers in the area of stroke or supporting people who have had a stroke, etc. And very often, they're not stroke survivors, or they don't necessarily have to have a connection with somebody who is.

Bill Gasiamis 6:02

But it's always fascinating for me to meet people who make it their life's work to help other people who they've never met before, by deciding to dedicate the rest of their whole career to that space. And I'm not saying I'm not saying that it's strange or weird or anything.

Bill Gasiamis 6:21

It's just amazing, like, as a stroke survivor, that there are so many people out there trying to look out for us that we've never met, that your research and studies ultimately end up supporting people who won't be in your particular group.

Bill Gasiamis 6:38

Those findings will filter out through the community and they'll get absorbed into other programs. And will benefit, I know that I was benefiting from a whole heap of research that was being done when I was in therapy, trying to get my left side to activate again and to start walking again and start using my left arm again. And I was just so grateful.

Bill Gasiamis 7:00

And I just want to share that I just want to make sure you guys know that we're grateful that we have that. So when somebody says to me, I can kind of be on the

podcast to share some success that we've had, or some stories or some funding or whatever it's like, sure ab.

Dr. Heidi Jansen 7:19

Yeah, I think for me, I, there's many aspects of physio you can go into. And of course, you've got your musculoskeletal. You've got your respiratory, I think because I did do a little bit of musculoskeletal and other Ward-based physio before I specialized. And I think for me, I do work and my work has to have a purpose or a meaning.

Dr. Heidi Jansen 7:25

It's got to be making a difference. And sometimes maybe it just comes down to what's the driver? For the person? And for me, I can see that. Yeah, I want to be involved with making a really, can we swear on this podcast? A little? A little, a yucky situation? It, looks, yeah, totally better for people.

Dr. Heidi Jansen 8:18

Because I think as a therapist, I always try to work with someone like it's my mother, it's my friend. Because if this was my mom or my friend, what would I want to make sure they had access to? And how would I want to work with them?

Dr. Heidi Jansen 8:34

And in terms of the research, the driver is that for me, the best way to drive change is being involved in work where you can produce evidence. Because otherwise, you're stuck in a system. And you get frustrated with the politics, the lack of resources, the inefficiencies, and it's like, well, how can I make a difference to this group of people, and that's gathered the evidence to make make it easier to argue settings to be better.

Bill Gasiamis 9:07

It sounds like it's a very hot lead with and then and then it's sort of brain rain lead in that it sounds like you know, going through that process with thinking that could be you know, that that's, I'm going to help that lady as if it was my mum, or that person as if it was my mum is a really hot lead, and that's what generates purpose or creates purpose.

Bill Gasiamis 9:33

And then the head comes into that ladder and kind of goes, alright, so how are we going to get this done? There's a million ways we can get it done. Let's, let's see

how we can get it done. This similar feeling that I get from the podcast. My head is telling me you should not be doing a podcast. Yeah, I mean, it's ridiculous.

Bill Gasiamis 9:45

You know, you're unlikely to make any money out of it. And like unlikely to do any of this stuff, which is very true. It's very difficult to turn it into a profitable enterprise. Whatever my heart is going, my God, we've got to do this, we can't stop doing this.

Bill Gasiamis 10:05

The feedback that I get from people who tell me that it's benefited them is, is not something that I can walk away from because I know there'll be more coming, you know, one in four people are expected to have a stroke in a lifetime.

Bill Gasiamis 10:20

So there's gonna be a heck of a lot of us, and I'm grateful to be able to have a platform where people like you can have a platform, I consider it kind of like a joint platform. Even though I'm supposed, you know, the guy that's behind the holster.

Bill Gasiamis 10:38

It's nothing without the other people and semi-stroke survivors, we are just people who are injured through sometimes most of the times no fault of our own, and then we end up being isolated and if we're not supported, we don't do well, we don't recover.

Bill Gasiamis 11:01

And we really, I particularly love it when people are doing the work in the background, that I benefit from that I didn't know it was happening. So it's lovely. Are you involved in a program called this theme?

Dr. Heidi Jansen 11:17

I'm sure having done a few podcasts and even being in the health community and research community, you're aware that acronyms are thought, you gotta have an acronym.

Bill Gasiamis 11:30

The thing and that's such a cool acronym, let me just say, I don't even know what it means but I like it already.

Dr. Heidi Jansen 11:37

So it stands for exercising, socializing, and thinking. And environmental enrichment model in the community, setting up districts, so it's a lot, but what it represents is, what the intervention or strategy is about, it's about combining exercise or movement socialization, or peer support, and cognitive stimulation or, or in the human realm, creative, like stimulating creative activities, that combination of activities.

Dr. Heidi Jansen 12:18

And what that does, is hypothesized to do in humans, at least is help promote brain plasticity, which I'm sure you're aware of many of your listeners are aware is the essential element of recovery after a brain injury.

Dr. Heidi Jansen 12:34

But it's also an essential element for normal brain development. And I can talk about that a bit more. And so it's those three elements that we're combining in a community-based model. And delivering that through an NGO, or a community care provider in the real world.

Dr. Heidi Jansen 12:57

And looking at the effects that it has on people's level of independence, mood, and quality of life, and not just theirs, but they support people or their carers. And so it's a bit of it is a big story because it's a big vision.

Dr. Heidi Jansen 13:15

But the essential part of it is that we're trying it out in the real world from the very beginning, because as a researcher, another aspect I'm passionate about is developing and evaluating things that are going to be sustainable beyond the project and because, again, you've probably seen it, been experiencing it, you know, researchers come up with a sexy new idea, test it, yes, it works, or no, don't have any more money.

Dr. Heidi Jansen 13:45

I gotta find someone to run it or philanthropist or someone to just, you know, donate. So we're trying to work with an NGO to deliver this co-designed model. And from the very beginning, see how we can make it sustainable and feasible, and then measure the benefits of that. Both for the people who are delivering it, but importantly, the people with stroke, and they support people.

Bill Gasiamis 14:14

So it's been going on for about 12 months already. Tell me about how somebody might get enrolled, and then what the steps are, and how you follow them through the program. And then what happens after?

Dr. Heidi Jansen 14:28

So people can in our area. So at the moment, it's just running in Newcastle, but we received some funding a year ago from MRF medical research future funds to roll it out in regional communities. Newcastle is somewhat regional and is classified as Metro.

Dr. Heidi Jansen 14:51

For this evaluation and development, we're starting in Newcastle but then we'll be going into more we'll regional areas like Maitland and then Manning, which is on the mid-north coast of New South Wales. But at the moment, we've run it for 12 months in Newcastle. We've interviewed the people who have run it and the people who participated and everybody loves it.

Dr. Heidi Jansen 15:19

And what they do is they can come at any point after their stroke, they don't have to wait until rehabs are finished. And they can have any level of ongoing challenges after their stroke to have to meet some criteria. And then you can come to the service self-refer or be referred by a health professional. And you come and twice a week, we'll join another group of people with stroke, led by a physio to do 30 minutes of exercise.

Exercise And Stroke Recovery



Dr. Heidi Jansen 15:50

And it's not very long, I know. But when we co-design that, back in 2020, I went to a group of stroke survivors, their support people, health professionals, artists, and venue providers, and we all went, Okay, so I presented as these are the fundamental elements that we have to have because this is what the science tells us that when we look at animals that recover from a stroke in an environment where they have access to greater opportunities to combine physical, cognitive and social activities.

Dr. Heidi Jansen 16:25

It promotes brain plasticity and improves motor function. And there's some indication that it helps memory and learning. So based on the science, we then say, well, what does this look like, for want of a better word in a human model? So people with stroke, it's got to have those three elements.

Dr. Heidi Jansen 16:44

And they're like, well, we don't want to exercise for too long. Yeah, well, because people get tired. Yeah, I hear that. But as a physio I sit there and say, Okay, well, it's going to be a quick 30-minute, sort of tough 30 minutes if we want to get that actual element in. So they do 30 minutes of exercise, and then they break for tea and coffee and have some yummy food, and share this.

Intro 17:13

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?

Intro 17:30

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

Intro 17:43

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.

Intro 17:57

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, but they'll also help you take a more active role in your recovery, head to the website now, recoveryafterstroke.com and download the guide. It's free

Dr. Heidi Jansen 18:15

Stories and of course they share their stories throughout the whole time there. But there's that opportunity to feel safe. And that's what people say is they feel safe being amongst people that they know, know, how they are and what they feel. Not all the time.

Dr. Heidi Jansen 18:32

But you know what I mean? Like that, that shared experience. And then we'll go into 90 minutes of movement to music. So dancing, we call it movement to music, because many people will say I don't dance, and it's like, well, you're just moving to music and you're doing it in a chair. And then eventually you're standing and then.

Bill Gasiamis 18:55

That's most men, most men.

Dr. Heidi Jansen 19:00

No, it's so the stories have been fabulous, like people that often end up quite resisting, go, I'm not gonna do that, I won't be able to do that. And then when they try it, they go Oh, actually, I can do that. And is that which is I can see how it's valuable. So 90 minutes of movement to music or 90 minutes of visual art led by an artist so the movement to music is led by a dancing therapist.

Dr. Heidi Jansen 19:26

And then movement to the art is led by an artist practicing artists. So one with your gallery and training. And then so it's a 10-week program. So twice a week they come exercise, socialize, and do a creative activity.

Dr. Heidi Jansen 19:44

And then they swap that creative activity so everyone gets an opportunity to try the art or try the movement to music and they do that for 10 weeks and we do some measures at the beginning. Eat before they start at the end, and then three months later, we check in to see how they're doing.

Stroke rehabilitation program's effectiveness



Bill Gasiamis 20:07

So it sounds like it's a cool extension of your standard, go to therapy, do that, and then go home, which is what I experienced. And it was quite tedious and annoying to do. But I had to do it, of course, and I wanted to do it. But it made it monotonous I had to get up in the morning, get ready, get prepared, make my trip, do my 30 to 40 minutes, and then go back.

Bill Gasiamis 20:37

And it was a three-hour round trip, like the whole exercise, but Tommy got ready and got there, had my session, and then left and went home, there was half my day gone. And to be honest, it got in the way of getting back to regular life, what I consider regular life, which is, which is binding, kind of some kind of an outlet, creative outlet, call it at night catching up with friends or things like that.

Bill Gasiamis 21:09

So I like this because it seems like what it's doing is rolling therapy into being creatively actively involved with something beyond just the therapy, and then the refreshments, the catching up. And it's the social side of it.

Bill Gasiamis 21:29

So it just seems like a real perfect way to go about therapy because it involves other people. It involves using that other part of your brain the creative part which I could do sitting down, I don't have to be fit while I'm being physical. And it just seems like it would be fun to attend.

Dr. Heidi Jansen 21:54

Yeah, I think the feedback we've received, people love it because they have a community, I think the community. So an example of that is the fact that we had a 12-month anniversary, to celebrate the success of running for 12 months. And pretty much you know, about three people that have been to the program came back.

Dr. Heidi Jansen 22:18

So I think it was close to 30 of 35 people. And they came and at the event, we had a little bit of an acknowledgment of where we have come from over the years in terms of the background, that we had the people with stroke, their family, there and their family loved being there because they could, they didn't always come to the program because we give sought to support people the option you can stay if you like, you're welcome.

Dr. Heidi Jansen 22:45

But you don't have to, and some people often will just come and if they know that their family or friends are safe, they will then have a little bit of respite. So it was it was like a sharing of a well, this is what the steam was about.

Dr. Heidi Jansen 23:00

And many family members were very appreciative and quite emotional, to see what their friend or family had produced because we had an art gallery. So we had an art exhibition, we had a trial of movement to music, we had videos of people participating, and we had over 100 people at the event.

Dr. Heidi Jansen 23:23

So we had the people who sponsor here, and I think I'm off track a bit, but they love it. They love going and people want to come back. And that's what we're working at how can we get people to utilize their existing funding sources, which are probably like My Aged Care or NDIS to keep coming back to this program?

Bill Gasiamis 23:47

Yeah, so I was going to then ask you Okay, so how do you clinically evaluate the program? So is it is it? Do you do baseline interviews with the person and how they're feeling? Tell me a little bit about how you measure the benefit that that person has experienced.

Dr. Heidi Jansen 24:07

Yeah, so the other thing that we asked in the codesign was, you know, how do you

want to be, you know, what sort of things do you want to measure? And when you're talking about therapy, one of the things I think people love about esteem is that it's not goal-focused. Right? How good we don't talk it's not about sir, okay? It's not about therapy.

Dr. Heidi Jansen 24:30

But inadvertently, we hope that people will get better with their walking stronger in their legs better in their balance, and more confidence so that they don't worry about falling. And they use their unaffected and affected arm all through the activities.

Dr. Heidi Jansen 24:46

But we don't so for the research, we evaluate them, but people don't have to participate in the research if they come just for the program. It's just to get to know you. And you know, what things have changed? changed that in terms of formal measures we don't do. It's just that we learn enough about someone to make sure we can make it safe maximize their participation, and ensure inclusivity.

Dr. Heidi Jansen 25:14

So the team learns about the person. And then it's about making the best experience they can for people during the program. From a research evaluation perspective, we do take measures, The baseline program ended three months ago, and they are around the level of independence, mood, quality of life, and social socialization.

Dr. Heidi Jansen 25:38

So how socially active Are you one of the things we want to look at is how participation in the steam helps people to then feel confident, to go and connect with other things in their community, and other people, because I think, from observing people's growth, that's what we see is the participation in activities that aren't therapy.

Dr. Heidi Jansen 26:03

And that doesn't have a goal, it builds people's self-efficacy, and they go look at what I can do, I have had a stroke. That's one thing, that's not all with me. And I'm also an artist, and I can also move. And I can also talk with other people. I think sometimes therapy goals. I don't know I am a physio and they're important.

But if you don't achieve them, I don't know how valuable that is for people's confidence.

Redefining identity after stroke

Bill Gasiamis 26:35

I can, I can tell you. So stroke survivors will often tell me it's 12 months past stroke, and I can't walk it. And they're devastated. Because somebody said to them, and they pick that up, you know, like in the periphery, somebody said, are, you'll be back on your feet in 12 months, and it's like, Oh, my God, that's terrible.

Bill Gasiamis 26:55

Now that that person hasn't achieved that, because they think that 12 months is the window, and if it doesn't happen, then it doesn't happen. So I've talked about it a lot. And I encourage people not to set deadlines, they can set milestones, I'd like to walk again. But that's it, don't make it any more detailed than that.

Bill Gasiamis 27:17

And that means that you can always work towards walking. And you also have to change what walking looks like it means, because it may still be walking when you're walking with a crutch, within an AFO, or with a whole bunch of other support. And that is more important than quote unquote, walking properly, or the way you used to before the stroke.

Bill Gasiamis 27:42

So it's to change the definition of walking so that it's more easily able to be achieved. And also to take away the timeline by which you have to walk on it. And then, and then what that does is that just allows you to go on a walk or jog a journey to walk again, soon, one day, at some point. And that's far better for the emotional part of the recovery.

Bill Gasiamis 28:11

And what you're talking about is I can paint or I've created this or I've made that that enables the identity of that person to become whole again, because the assumption for a lot of stroke survivors is that now that I've had a stroke, I'm no longer all the things that I was before that. And it's like, wow, a stroke is not that dramatic, I understand how not allowing you to participate in an activity makes you feel like you're missing out.

Bill Gasiamis 28:42

But that doesn't change who you are if you can still be somebody who participates in sports. That doesn't look like the type of sport you participated in before. And the Paralympics is a perfect example of people attending sports and participating. And being athletes and sports people, even though they wouldn't participate in the same way that they did before their brain injury, whatever that was.

Dr. Heidi Jansen 29:14

And I again, appreciate it as a person who hasn't had a stroke, but from working with people over many years, that journey around accepting what I am or me now. It's different for everybody. So some people will be like.

Dr. Heidi Jansen 29:35

Well, I'm not going to be a success until I get back to the person I used to be and you're talking about. The thing that we try and help people with is you are not your stroke, though you're still you and you still love the things you love and you can do the roles you do. They just might look different. But some people struggle With that, and I can understand why.

Dr. Heidi Jansen 30:02

But sometimes it can be a very big block in that sort of learning to return to life again. And I wonder if steam provides an avenue, because people, they're all they've all had a stroke. But they're all celebrated for being the person they are not what they can do.

Dr. Heidi Jansen 30:24

You know what I mean? Yeah. And then that feels so safe. And like, I've got friendships here, and look at me creating these things, and everybody thinks they're great. It doesn't matter that I'm not exactly how it was before these people like me, for me how I am now.

Bill Gasiamis 30:41

Yeah, or the person that they are not the tasks that they do or don't do. I have some great friends who are stroke survivors who I never would have met was the stroke. Yeah. And a lot of them are in Melbourne because that's where I hang out with stroke people more than I do anywhere else. I mean, that's where I live.

Bill Gasiamis 31:05

And they went through their struggles at the beginning of redefining their life. So

I redefining who they are, what they are, and how they attend. But, but, they still were always them. So this their personality was always their personality, it was always the same. And we didn't lose that they didn't lose their personality or didn't evolve when they achieved goal x, or they didn't achieve goal x.

Bill Gasiamis 31:39

So what the tasks that they were able to do or not do, were not relevant in our friendship, but he was like, Yeah, I like you for who you are. And that's about it. And everything else is a bonus. And what I found was that they have that many of them have re what's the word? Oh, my gosh, around blank, that many of them have reinvented themselves.

Bill Gasiamis 32:08

And then it's cool, because they brought their thoughts, their ideas, their previous experiences, and they've applied them to this new version of themselves, this reinvention. And, and it's bloody great to say it's like, really amazing to see because one of the gentlemen, Antonio, who I interviewed, at the very beginning of this podcast series, maybe in the first 20, or 30, episodes.

Dr. Heidi Jansen and the program for people with neurological conditions

Bill Gasiamis 32:37

He had a stroke, and he was a guitarist, so he was not able to pick up his guitar again. So he started playing the one-handed piano. And now he's a music producer. And amazing, he's reinvented himself. And it's because of that whole idea of okay, he got curious as to what can I do, as opposed to what can I not do? And then focus on that.

Dr. Heidi Jansen 33:04

Yeah, and I think that loss of who I was, or that loss of identity and changing roles, is something that I have observed is challenging, but as you say, if it's framed differently, well, what can I do? Who am I now? And what are the opportunities? But yeah, that's challenging.

Bill Gasiamis 33:27

Yeah, can be. So Steam is now getting funded for an additional year. Is that right?

Is that how things work?

Dr. Heidi Jansen 33:38

So we got some money to help embed or deliver it with a new service provider. So at the moment, we're working with Mercy Services in Newcastle, we got some funding to run it with Maitland Community Care, in Maitland. And again, what we will do as we did in Newcastle is use that money to help train up their staff to deliver it so that we can evaluate the benefits.

Dr. Heidi Jansen 34:05

And whilst we're doing that we work with the organization to work out. So people that are wanting to keep coming to this program, how do you how do they use their funds to keep coming back because it is quite expensive to deliver? When you think you've got a physio involved to allied health assistance to support the movements and the creatives, and we've got an artist and we've got a dance therapist and we've got a program coordinator. So all of the resources are in the people.

Bill Gasiamis 34:36

Six people.

Dr. Heidi Jansen 34:37

Yeah, but it's not dissimilar in terms of costs to what people might be accessing through NDIS or other My Aged Care Programs. So it's just tweaking what we might need to do and educating the community about how they need to articulate what they need in their life. packages to be able to access the steam.

Dr. Heidi Jansen 35:03

Because yeah, that's the goal is we'll train you up in his program, with the goal of it being accessible long term. And I think eventually, especially in regional areas, we may need to make it more feasible by including people who have had other life-changing events such as a traumatic brain injury, perhaps, or people living with Parkinson's. So it can be feasible because when you run anything in the group, you need a certain number of people to break even with your costs.

Bill Gasiamis 35:37

Ah, I see. Yeah, so numbers are essential. Definitely. Okay. There is no doubt, that people experiencing traumatic brain injury, despite their neurological conditions often have a lot of similar challenges that they've overcome.

Bill Gasiamis 35:54

I relate to a lot of people who are experiencing other neurological conditions because the deficits manifest in similar ways, you still have the same type of deficits and challenges to overcome. So have you noticed that people who started 12 months earlier, or how long does the program run for 10 weeks? So can they read and roll and come back again?

Dr. Heidi Jansen 36:28

So again, for the evaluation, we're just at the point of putting people through once. But the vision is once because we're currently running at 110 people per program, we're looking for a bigger venue to blow that out to 16. So it's more cost. What's the word? It's more accessible for people with their packages because you don't want them to be burning through all the money that comes in.

Dr. Heidi Jansen 37:02

And so when we have a larger group, I envisage that we'll be able to both support people running through the program for evaluation, but also people coming back on going so if you want to, for use of a better word, a maintenance program, but it's, it's not about maintenance.

Dr. Heidi Jansen 37:19

The big vision is to have this program in communities where people can come and go from it as they feel they need based on where they are at a point in time. So they want to use their money on it for 12 months. Sure. But if I only need a bit of a top-up, because I'm feeling X, they can leave whenever they want. That's the long-term vision.

Bill Gasiamis 37:41

Yeah. Excellent. So are you looking to enroll people now?

Dr. Heidi Jansen 37:46

Yeah, we are aware, we're enrolling people in Newcastle and then also in Maitland, and we'll be starting, hopefully, the program in Maitland in March of next year. And then Manning hopefully by the end of next year. Yeah, for taking interested people.

Dr. Heidi Jansen 38:04

The challenge, I think, for your audience, possibly Bill is that it is based in New South Wales, and it is based in specific communities. Eventually, I'd love to have a

hybrid model where people could be accessing it, or a similar part of it through virtual means. And I think virtual is good, but there's so much value in that person-to-person contact.

Bill Gasiamis 38:30

Yeah, virtual is not the same. I still do attend a few virtual aphasia groups and a few other groups. But it's not the same, but it's better than nothing because sometimes nothing is the only option. Yeah, and even though I'm in Melbourne, and my audience is global, it doesn't mean that we can't share these stories and invite people to get curious about these programs because they might branch out, they might be co-collaborators in other countries who want to share findings, etc.

Dr. Heidi Jansen 39:07

There was something I was going to mention when we were talking about enrolling. I can't remember now, it'll come to me.

Dealing with self-esteem and aphasia

Bill Gasiamis 39:15

It'll pop up in a minute. So there's an opportunity for people who are interested in this type of program overseas to get curious about what you guys are doing, how you've found that, what challenges you've overcome, and all that type of thing.

Bill Gasiamis 39:31

So I don't see why, why that can't happen on this sort of platform, because we've got to get it out there and there could be some people in New South Wales that have access to Newcastle who can come to Newcastle.

Bill Gasiamis 39:49

And what I'd love to happen is that this episode is shared by people in your community in your organization to their local community, and support groups, be aphasia groups, be it, you know, whatever therapy groups are happening in and around your area, because there'll be stroke survivors lurking in those other spaces as well, you know, that haven't stumbled across esteem. Now, what I love about esteem is that it helps to improve people's self-esteem.

Dr. Heidi Jansen 40:23

That's right. That's right. I don't know how I made that happen, but I just did it in

terms of the acronym. Anyway, acronyms are always something you think about all the time. And sometimes you come up with good ones in the shower, in the grocery line, things like that.

Bill Gasiamis 40:44

And usually, they're terrible. And they don't have another layer of complexity to their meaning. But this is awesome, because it has that, and it does, that's exactly what therapy sessions that are interactive in blue involve people who are like-minded, who do not record what you suppose, and who are not goal-oriented. That's what they do. That is a goal in itself, if you can improve that person's self-esteem, well, I think that's a huge goal.

Bill Gasiamis 41:17

And then that gets them curious. I know, because of me, if somebody proves to me that I'm capable of something that I thought I was not capable of, then what it does is it gets me curious to go, what else can I do? Or what else am I capable of? Or how else should I attend them participate?

Bill Gasiamis 41:35

And this podcast thing is nothing but somebody going to me, you could probably do this online, where I used to previously. Just do this locally, for the Stroke Foundation here in Australia, I would go and share some information with a local community group about Stroke Awareness and Prevention.

Bill Gasiamis 42:02

And that was like, Oh, that's pretty cool. And I could do that forever. But it only reaches so many people while this goes global, and we have a larger impact. So that's how I got sucked into that somebody told me that I was capable of a lot more than I thought, and I went down this path.

Dr. Heidi Jansen 42:23

I think what you're doing in a way, sharing stories and giving people an opportunity to share their story is not dissimilar to a steam because that's what happens. When everyone comes together all the time they learn a little bit more and they hear another person's experience, which is what you're doing.

Dr. Heidi Jansen 42:42

And they go, Oh, okay, I didn't know you could do that, or that's a great idea. So the most influential people in that community, people gotta have shared your

experience. So I think you're doing great work sharing everybody's learnings and experiences.

Bill Gasiamis 43:01

Thank you. I think you're doing great work too thank you for being a guest on my podcast. I appreciate it. Good luck with the next 12 months. I look forward to hearing from you again. If there's an update that you're happy to share, please reach out.

Dr. Heidi Jansen 43:16

Wonderful. Thanks so much, Bill. And thanks to your audience for taking the time to hear our story.

Bill Gasiamis 43:22

Well, thank you for joining us on today's episode. Remember to grab a copy of my book *The Unexpected Way That a Stroke Became the Best Thing That Happened* by going to your local Amazon, typing in the title, or my name Bill Gasiamis.

Bill Gasiamis 43:37

If you're an Australian buy from the Australian link that is available in the show notes or the description of the YouTube video, and I will sign the book for you. As always, to learn more about my guests, including links to their social media and other pages. And to download a full transcript of the entire interview please go to recoveryafterstroke.com/episodes.

Bill Gasiamis 44:02

Thank you to everybody who has already left a review means the world to me, you are helping others in need of this type of content to find it easier and that is making their stroke recovery just a little better. If you haven't left a review would like to the best way to do it is to leave a five-star review and a few words about what the show means to you on iTunes and Spotify.

Bill Gasiamis 44:26

If you're watching on YouTube comment below the video I respond to all the comments on my YouTube channel. Like the episode and to get notifications of future episodes, subscribe to the show. If you are a stroke survivor with a story to share, come and join me on the show, the interviews are not scripted.

Bill Gasiamis 44:47

You do not have to plan for them all you need to do to qualify as a stroke survivor who wants to share your story in the hope that it will help somebody else who's going through something similar. If you are a researcher who would like to share the findings of a recent study or you're looking to recruit people into studies, you may also wish to reach out and be a guest on my show.

Bill Gasiamis 45:08

If you have a commercial product that you would like to promote that is related to supporting stroke survivors to recover there is also a path for you to join me on a sponsored episode of the show. Just go to recoveryafterstroke.com/contact.

Bill Gasiamis 45:24

Fill out the form explaining briefly which category you belong to. And I will respond with more details on how we can connect via Zoom. Thank you once again for being here and listening and participating leaving your comments and telling me how much the podcast means to you. I appreciate you see you on the next episode.

Intro 45:45

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

Intro 46:02

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Intro 46:18

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Intro 46:30

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Intro 46:46

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Intro 47:09

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