## Can High Dose Physiotherapy Improve Walking Post Stroke | Dr. Kate Scrivener

Dr. Kate Scrivener is leading a team of researchers to discover if high-dose physiotherapy can improve walking after a stroke.

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Dr. Kate Scrivener 0:00

So there's no restriction on age. For time post-stroke, we are looking for people who are more than six months after their stroke, but less than eight years, the other criteria, so it's really for people who can walk but would like to walk better. And I look at it in a few ways based on kind of what people tell me. The kind of

common things they tell me.

#### Dr. Kate Scrivener 0:28

I can do X, but I want to do Y. So they have a clear goal. And what's motivating them to kind of sign up? The other thing that sometimes people will say is that something's happened. So they might have had a fall and they say, look, I had a fall, just feel like it's set me back and I want to get on and have a boost to try and get back to where I was.

#### Intro 0:59

This is the Recovery after Stroke podcast. With Bill Gasiamis, helping you navigate recovery after stroke.

### **Introduction - High-Dose Physiotherapy**



#### Bill Gasiamis 1:12

Hello, and welcome to episode 257 of the Recovery after Stroke podcast. My guest today is Dr. Kate Scrivener. Senior Lecturer in physiotherapy in the Department of Health Sciences from Macquarie University in Sydney, Australia. Kate is conducting a study specifically designed to see if it is possible to improve the walking ability of stroke survivors who are at least six months post-stroke, but no more than eight years post-stroke and are currently walking, but have some walking deficits.

#### Bill Gasiamis 1:45

The study is being conducted in two locations including Sydney and Melbourne.

Kate is looking for volunteers who may be interested in participating and who are based in Melbourne to sign up and be a part of the study.

#### Bill Gasiamis 1:58

The Sydney group of volunteers has already been filled and the study will commence on the first week of July 2023. The Melbourne group will hopefully be recruited and ready to participate in the study by August 2023. Go to recoveryafterstroke.com/episodes to get all the links to more information on the study and download the PDF flyer with further information.

#### Bill Gasiamis 2:24

If you are in a country outside of Australia, this conversation may also be interesting for you if you want to improve walking after a stroke and you're curious about new ways and other ways to go about it. Kate Scrivener, welcome to the podcast.

Dr. Kate Scrivener 2:43 Bill thanks for having me.

#### Bill Gasiamis 2:45

My pleasure. Thanks for being here. Tell me a little bit about your background what you do and how you managed to be in the situation where we're chatting today.

### Dr. Kate Scrivener's Medical Background



#### Dr. Kate Scrivener 2:54

So I'm a physio by background Bill. And I've worked particularly in stroke rehab in various forms for almost 20 years. I'm from Sydney Australia, and now my primary role is an academic role at Macquarie University, where I teach physiotherapists about neurological rehab and research in particular in stroke rehabilitation.

#### Bill Gasiamis 3:26

How did you get to be involved specifically with physiotherapy in the stroke field?

#### Dr. Kate Scrivener 3:34

Yeah, I don't know, I don't know I have some family connection to stroke. So I wonder if that's it. But I set out as many physiotherapists do to, you know, work with healthy sporting people. And then as you know, in my experience at university found that it was much more interesting and much more rewarding to help people on their recovery journey after a stroke. And that's where I landed ever since.

#### Bill Gasiamis 4:06

The cool part of Physiotherapy is you always hear about people working in Sports Therapy, or, you know, for the biggest football team or the most, you know, famous tennis stars or whomever. And it makes sense that that's kind of an area that attracts a lot of people's interest at the beginning.

#### Bill Gasiamis 4:29

But it's a very small niche because there are only a limited number of football teams. And then there are also only a limited number of superstars that you can get lucky enough to work with. So how did your early career unfold? Where did you find yourself getting your experience from?

#### Dr. Kate Scrivener 4:51

So really, I worked within the public hospital sector and just did my very best because if anyone knows the public hospital sector, they like to give you varied experiences, which is great. But I knew I loved stroke rehab pretty early. So I did my very best to get as much experience as I could in stroke rehab until I was able to kind of get a job that was completely full-time in stroke rehab, which was fantastic.

#### Bill Gasiamis 5:28

So what are some of the differences between working with we'll call them nonstroke people, stroke people? I know there are heaps, but what stands out as being some of the differences, I suppose, in the challenges working in that space, oh,

#### Dr. Kate Scrivener 5:45

Bill, you would know this more than I do. I think it's just such a privilege time to work with someone because, you know, I can't even imagine what it feels like to be just living your life and then, in an instant, have something pretty bad happen. Most of my stroke experience is at a hospital in Sydney called Bankstown Hospital, which has a comprehensive stroke in it so acute right through to rehab.

#### Dr. Kate Scrivener 6:18

And so you'd meet people the day of or the day after their stroke, and understand the impact of it on their life. But then, you know, have the privilege of working with them, or alongside them to build their recovery. And yeah, I just feel like it's a very rewarding physio because you can have such an impact. And you can help people on that journey. Sometimes Bill doesn't quote me on this, but when you're working with people that are already healthy, and they have, you know, something that sore, for me, it just doesn't have the same meaning.

#### Bill Gasiamis 7:03

It doesn't have the same meaning for people who are healthy as well. So as somebody who was very normally situated in the world of physical experience, I didn't take a lot of satisfaction in going to the gym, or running, although the outcome of playing soccer, for example, was fun because I got to hang out with people, I never realized how important it was to be able to do those things, without thinking twice about them.

#### Bill Gasiamis 7:47

And then I could say, I took it for granted, which is pretty common and fair. And then you go about life, and then all of a sudden, that's taken away from you. All you wish is can I get back to what I was like before, or finally everything was like it was before, and that isn't constructive. But then the goal of getting up and walking in the wind of recovering your ability to move independently is a massive achievement.

#### Bill Gasiamis 8:20

It's a massive accomplishment and something that changes completely the way that you experience your physical body and the way that you experience how you identify in the world that you were raised in and that you've spent the majority of years in. And when you have such a big contrast of this is what life was like for 37 years and now this is what it's like going on from there.

#### Bill Gasiamis 8:50

It's a really difficult thing for some people to come to terms with. And what we often hope for is that there's going to be an unlimited, never-ending supply of occupational therapy, physiotherapy, physical therapy, any kind of therapy that's going to get us where we want, but it often doesn't come.

#### Bill Gasiamis 9:13

How much access do you have to the patients that you are introduced to when you're in a hospital with them? And then how does that relationship evolve after a few weeks or months? And their recovery is sort of starting to evolve into the next phase?

#### Dr. Kate Scrivener 9:32

Yeah, that's such a great question. I think you're so right about walking and being tied to people's identity, you know, people always tell me they want to walk again. And when they do, it's like, yeah, they've jumped over a huge hurdle to finding some of themselves again.

#### Dr. Kate Scrivener 9:58

Yeah, so I think what's interesting is I've worked in the public hospital system. But now or in the last few years, if I work at all, it's in the community or the longer term after stroke. And my interest has turned to that group.

#### Dr. Kate Scrivener 10:13

Because I think it's what your question was hinting at Bill that we spend a lot of time with people generally when they're in hospital. For some people, it's a bit variable, what you have access to when you leave the hospital, but most people will have access to something in the weeks or months after leaving the hospital.

#### Dr. Kate Scrivener 10:35

But then what people have access to ongoing in the longer term after stroke in Australia anyway, is highly variable. varies by age varies by what, you know, sector of funding you can go into varies by postcode, and what's in your local

community. So there is, yeah, huge variability. And I think the honest answer is some people, when they're months or more, after their stroke have access to almost nothing, if not nothing.

# Access to physical and occupational therapies in older ages

#### Bill Gasiamis 11:13

Yeah. And you mentioned age being a variable. At what age? Do you see that support being reduced? It's my experience that in older ages, there seems to be less of an opportunity for somebody to access physio and occupational types of therapies. Is that correct? In what do you see? And do you have some sort of an understanding as to why that is? Why it is that older people get less, what's the word support or services? Where, in my mind, it seems like they should be at the top of the priority list and get more. But that's not the case.

#### Dr. Kate Scrivener 12:04

It's an overall picture, that's my experience too. And if we look at support available in Australia, our disability support is for people who are 65, or younger when they have their stroke. But as we all know, I'm sure many people over 65, when they have their stroke, which in Australia puts you in the aged care sector.

#### Dr. Kate Scrivener 12:36

That is changing but historically has not been very goal or participation-driven. It's been very minimalistic, in terms of actually achieving what the older person wants to achieve. I hope it changes. I think the Aged Care Royal Commission has suggested some changes to that.

#### Dr. Kate Scrivener 12:59

Either way, we still have a different system, depending on how old you are, which I think is not great for a condition like a stroke, which does span the age brackets, you know, I don't think we should have different systems, different pockets of funding, depending on how old you are when you have your stroke.

#### Bill Gasiamis 13:26

Well, it's a form of discrimination. I mean, it's probably the most obvious form of discrimination where people that experience a disability or an acquired brain

injury or something of a serious nature after a certain age, we'll call it after 65, at least in Australia, and I see it around the world anyway, because I interview a lot of people around the world.

#### Bill Gasiamis 13:47

But in Australia, because we're both here. It seems to be discriminatory. And it's so plain and so obvious, yet there is nobody paying attention to it. We're all going to be hopefully older than 65 at some point in our lives. And that means that the people who are discriminating against older people are creating a system that's going to discriminate against themselves when they get older. And I just said it's completely bonkers.

#### Dr. Kate Scrivener 14:21

Well, look, I'm pretty passionate about it. I wrote an article about this in the Medical Journal of Australia recently and the Physio Association picked it up, which was great. I don't know if I'm quite on that line. Like I'm hopeful that older people will get better funding in this space. It does still bother me that it's different.

#### Dr. Kate Scrivener 14:46

And I think it makes a complex system and system that's pretty hard for people to understand and navigate. But there's probably no I think the quick solution is helping to fix The aged care funding in the long term wouldn't have been nice. If there was one source of funding to meet people's needs.

#### Bill Gasiamis 15:10

Yeah, seems like the system is fragmented. As a result, people can easily fall into the cracks, and therefore, it's somebody else's problem in another department and not ours, I imagined that the aged care department is probably screaming out for funding or more funding or better funding.

#### Bill Gasiamis 15:28

And they would be constantly going through the process of trying to advocate for their community, or the people that they're allocated to care for, and they would be struggling. But it's great and I never knew about the fact that there is some work being done to potentially create awareness in that space.

#### Bill Gasiamis 15:54

Now, I am going to remind you that at the end of this interview, we get the link to

that particular article that you wrote, so that we can share that with the people who are listening. Most people who are listening might be interested in reading your perspective, and that'd be good if it gets a little bit of extra traction.

Dr. Kate Scrivener 16:14

No problem.

Bill Gasiamis 16:16

So in your space, as a lecturer is a neurological physiotherapist. Is that different from a physiotherapist? Is that another kind of part of physiotherapy that additional skills or knowledge that you require to get into that space?

#### Dr. Kate Scrivener 16:42

Look, there are kinds of levels to qualification. So every physiotherapist who graduates from University will be trained in neurological physiotherapy, and trained to work with people after a stroke. It's part of the core curriculum for their degree.

#### Dr. Kate Scrivener 17:04

But then after you finish that you can go on and do further study to specialize in neurological physiotherapy. And there are a few pathways. To do that, to gain kind of extra qualifications. I went down the research pathway. So I started my Ph.D. and have continued to research stroke.

#### Bill Gasiamis 17:36

Yeah, tell me about some of the research projects that you've done to date.

#### Dr. Kate Scrivener 17:40

Yeah, so I guess my interest in walking after a stroke started during my Ph.D. So in my Ph.D., we looked at recovery of walking in a big group of 200 stroke survivors, to see how many recovered walking and whether were there any ways we could predict who would recover their walking, I also have a strong interest in intensity or high dose motor training after stroke.

#### Dr. Kate Scrivener 18:13

So again, that started in my Ph.D. but has kind of flowed through my career. And, you know, I've done technology research to try and boost intensity, just doing really good motor training, but doing enough of it. And now, my research probably sits more in the community in terms of improving, walking, preventing

falls, and improving life in the longer term after stroke.

#### Bill Gasiamis 18:49

That seems like an awesome space, improving walking and reducing falls. Falls tend to be a big setback for some stroke survivors. I know a couple that has had some falls and as a result, broken limbs and then seems to have put their recovery back several years and challenged their mental health space around their ability to become more active, especially if they're older, and their ability to get back to life or overcome their deficits from a stroke.

# The High-dose physiotherapy research project



Bill Gasiamis 19:25

What is hope? What's the hope of this particular study that you're doing at the moment? What are you hoping to find? And how do they work? I've got no idea how these research programs work. So as soon as you reached out and said, can you promote a research project that we're going to talk about in a little bit because you're looking for people to participate? I don't understand how the process of it so where it starts from what happens in the middle and then what happens in the end. And then what might happen after that? Can you give me a bit of a rundown?

#### Dr. Kate Scrivener 20:04

Yeah, what a great question. It's not easy. It's pretty complex the whole thing. So typically, it starts from an idea. And an idea that kind of often develops over time and clinical experience as well as other research. And if we talk about high walk, the idea was, could we think differently about how therapy was accessed in the

#### longer term after stroke?

#### Dr. Kate Scrivener 20:37

Because we just talked about that sometimes it's very hard to access at all, and where it is accessed, it's often long and slow. You know, you might see someone once a week, you know, on an ongoing basis. So we kind of wondered, would stroke survivors prefer doing a short, sharp kind of burst of training, allowing them to focus on it for a few weeks, but then get on with their life for a while?

#### Dr. Kate Scrivener 21:12

And would that boost of training, boost them enough that it would be worthwhile and allow them some time, you know, at that improved level of function? So we kind of came up with an idea. But then you have to prove that your idea kind of works in reality, and that stroke survivors think it's a good idea, because there's no point sitting in the university with your idea, but it's not what people want to do.

#### Dr. Kate Scrivener 21:44

So then we did, I guess what you'd call a proof of concept study, where we tried it in a very small group of stroke survivors only five. And we just saw, could they do it? And what did they think of it? And perhaps the good news was, that they liked it, they attended. So it's a 45-hour program in three weeks. When we tested it, they attended about 90% of the sessions and had a really good rate of practice or exercise within the sessions.

#### Dr. Kate Scrivener 22:24

So that bit went pretty well. So then we thought, well, this seems like a good idea, let's run a trial of it. That costs money, so you then need to apply for money to do that. And we were very lucky that the Stroke Foundation awarded us a grant to do this research. So we're at the point now, where we're looking at High Walk in a group of 50 stroke survivors.

#### Dr. Kate Scrivener 22:56

And we proved it in a small group, we now need to take it out to a bigger group and see whether that holds. And whether it looks like in that group, there could be a benefit for people's walking. And if there is a benefit, can we get an idea of how long that benefit will last after the program? And that's where we are now.

# Qualifications to sign up for High-Dose Physiotherapy

#### Bill Gasiamis 23:25

Okay. So how do you go about choosing the stroke survivors to participate? Are there some criteria that they have to meet, for example? How soon after the acute phase do they qualify? And then, are there any restrictions on age at the moment? Is it an open thing? Tell me a little bit about the participants.

#### Dr. Kate Scrivener 23:54

Yeah, again, what a good question. So there's no restriction on age. For time poststroke, we are looking for people who are more than six months after their stroke, but less than eight years, and we're trying to the Strike Foundation to fund our research because it was in the longer term. So I think full credit to them for shifting the focus to the longer term.

#### Dr. Kate Scrivener 24:24

That is why there's that six-month minimum and eight years was just a number to try and narrow our group down a bit. And that's where research and real-life differ a bit because I think in real life, the program could be applicable, no matter the year's post-stroke, but for research, you need a bit of a narrower group, at least the first time you kind of research something.

#### Dr. Kate Scrivener 24:56

The other criteria, so it's really for people who can walk Look, but we'd like to walk better. And I look at it in a few ways based on kind of what people tell me the kind of common things, they tell me. I can do X, but I want to do Y. So they have a clear goal.

#### Dr. Kate Scrivener 25:18

And what's motivating them to kind of sign up? The other thing that sometimes people will say is that something's happened. So they might have had a fall. And they say, look, I had a fall, just feel like it's set me back, and I want to get on and have a boost to try and get back to where I was.

#### Intro 25:39

If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through

your mind, like, how long will it take to recover? Will I recover? What things should I avoid? In case I make matters worse, doctors will explain things that, you've never had a stroke before, and you probably don't know what questions to ask.

#### Intro 26:04

If this is you, you may miss out on doing things that could help speed up your recovery. If you're finding yourself in that situation, stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you it's called Seven Questions to Ask Your Doctor About Your Stroke.

#### Intro 26:23

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. Kate Scrivener 26:42

So probably that's the two groups of people that are contacting us and expressing an interest in the program.

#### Bill Gasiamis 26:49

Right. So I recall being in outpatient therapy to get my walking a little bit better, a little finer after the initial month in occupational therapy and visit and physical therapy in the Royal Melbourne rehabilitation clinic at any Parkville. And one of the awesome questions that I got asked was, What do I want to achieve about my walking, etc? And I said I want it to be able to run and not to run marathons.

#### Bill Gasiamis 27:29

Although some crazy stroke survivors are doing marathons and ultra-marathons congratulations to them. I wanted to run across the road in case there was a car coming. That was it. I can't run anymore in the way that I used to when I was playing soccer as an amateur soccer player, because of the leg response and it knows where it is on the ground. And all the stuff that goes with being that physical, that sudden shifting and moving is probably not conducive anymore to my abilities.

#### Bill Gasiamis 28:02

I can't be that physical with my body. But I definitely can run across the road and

get away from a car, or, you know, run two or three or four houses down the road. And not be too concerned about falling or tripping on a treadmill, I can run longer because there are no variables, and that's consistent. And everything kind of just flows. And if you put the treadmill on a slow pace, you can get into a good rhythm.

#### Bill Gasiamis 28:28

And even though feels weird on my left side, it's still relatively doable. But running for five minutes on the road in Melbourne on a footpath where there might be a tree root that's cracked the pavement etc. Puts too many variables in it so I have to focus and notice the ground more than focus on my rhythm and running.

#### Bill Gasiamis 28:56

So it was awesome. When they said to me, what do you want to be able to achieve I like that aspect of your study is that it gets to kind of personalize it without really personalizing it, you aren't making a specific program for everybody, but you're asking them and that feels like it's a personalized program specifically for them. Does that make sense?

#### Dr. Kate Scrivener 29:24

Yeah, 100% That's the plan. And in fact, that's really like working in the longer term and the community. Now for that exact reason that people you know, when you're in the hospital immediately after your stroke. It's life-shattering and you're just getting on your feet again, whereas down the road, there will often be a clear thing that you just want to get better at doing or that's limiting your life.

#### Dr. Kate Scrivener 29:53

And you can see how if you could do that, your overall life would get better I think that's cool. And as a physiotherapist, we have to ask that question. And we have to listen to people in terms of what would be meaningful for their lives, I think.

# Dealing with fatigue issues for research participants

#### Bill Gasiamis 30:14

Yeah, rather than you're putting your perspective on them and overlaying your supposed thoughts of what's best for that person, it's probably never going to be

right. Because you're not that person. You don't know what their life is like. One of the things I also picked up on that I liked about what you said is, that we've got on **Episode 250**, I interviewed with Dr. Amir Hadanny, and he's a hyperbaric oxygen therapy researcher.

#### Bill Gasiamis 30:42

And he's talking about doing what you said high dose, high dose, hyperbaric oxygen therapy, over a month, I think it was or maybe it was over 60 days, but what was interesting was the number of hours per day. And normally, I would say, well, a stroke survivor may not be able to do hours and hours per day, because there's a fatigue issue and things like that.

#### Bill Gasiamis 31:12

Now, I'm not sure if it's anecdotal, or whether or not your study of five people who you did the pilot on, got you this type of feedback. But I was wondering whether or not you guys noticed a difficulty with overcoming fatigue at the beginning of the program, and then the ability to deal with fatigue better as time progressed.

#### Bill Gasiamis 31:40

Because I know that exercise is amazing for the brain. And it helps to create new neural pathways. It helps to create serotonin and dopamine and all these amazing neuro processes. What did you notice the patients were like physically before and after their stroke? Hopefully, you noticed that they walking differently or more confident about their walking. What else?

#### Dr. Kate Scrivener 32:07

Yeah, the five people were pretty remarkable. And they were, you know, obviously very motivated people to try it. So they got through, actually, with very few reports of fatigue and really success. But that's a chosen group of five, we are now broadening it out. And that's something that we are interested in, we are not sure that the whole group that does the high walk program will be able to attend every day, or do the three hours a day.

#### Dr. Kate Scrivener 32:46

And that's one of the things we'll measure because we're not sure what the exact right dose is. the right dose, the right duration, for people after stroke, so one of the biggest things is to know what they can do. And we also want to know what

impact that has on the rest of their life. So if they're coming to the program three hours a day, what does their kind of activity or participation in the rest of the hours of the day look like?

#### Dr. Kate Scrivener 33:19

So that's yeah, some of the really interesting things will gain from this study, I guess we think, Well, I don't know, you could probably do more than three hours, but we think three hours is a pretty big amount.

#### Dr. Kate Scrivener 33:34

And so we'll learn in this round of the research what actually really sticks and perhaps what it should be, which then hopefully, if we get to go on, to do more research in this space, we'll use that information to refine the program. I think that's a really interesting idea about whether it helps build resilience or helps them feel less fatigued at the end of the program. We're about to find out.

#### Bill Gasiamis 34:09

I imagine my personal experience and the experience of some of the other stroke survivors whom I've interviewed on the podcast is that at the beginning, especially for me, so we'll say maybe around the 12-month mark, where I was probably starting to be the most active that I had been in the previous 12 months after, which was just before the brain surgery.

#### Bill Gasiamis 34:38

I noticed myself going for a bike ride so the bike ride was a gentle, mostly flat surface and then that might last an hour or two because I was taking my time, and then the rest of the day I would be completely wiped out. And the rest of the more afternoon would be on the couch watching TV doing nothing, and not participating in the day in any other way.

#### Bill Gasiamis 35:04

So that I could just be okay for the evening, usually that bike ride was happening on a Saturday. So it could be alright for the evening if we had dinner to go to or catch up with some friends or something. And then the next day would be a really slow start to the day as well, it seemed to have a residual impact, where I needed almost 24 hours to recover and feel better and another sleep in between.

#### Bill Gasiamis 35:32

As time went on, that decreased, so I needed to sit down and recover when I

needed to be on the couch for the next eight hours. You know, too slowly I started to creep back. And now I can say that if I go for a bike ride, you know, perhaps I do need to just like anyone who's had a massive bike ride. And for me massive is not what you know, a crazy mammal would ride you know, they wouldn't be doing 100 kilometers a day be like if I'm doing 20.

#### Bill Gasiamis 36:01

For me, that would be massive. But that started to decrease. And over time, my recovery needed to be an hour or two. Now my left-side deficits were more pronounced to me. But there was this weird thing that was happening. So my deficits were more but my walking wasn't worse. It felt stranger and worse, but it didn't look stranger and worse on the outside.

#### Bill Gasiamis 36:27

So there was this residual, there was this physical fatigue of just standard muscle fatigue, but the neurological fatigue had decreased. And it seemed to be that I was now dealing with physical fatigue, muscle aches, and pains rather than the neurological fatigue and the impact that had on walking.

#### Bill Gasiamis 36:53

So the neurological pathways were getting less strained, I suppose. Or they were getting better, stronger, something perhaps the other, the other side of it, they were improving their ability to manage the load of pedaling and holding on with my left side. And then what that did to the brain. And then I wasn't specifically someone able to use my cognition as, as I was at the beginning, where my cognition would also be the thing that I had to heal and recover and let rest, not just my physical part.

#### Bill Gasiamis 37:33

So I imagine because I'm because I've got like a window into the future. And I know your page, your participants, I imagine that some of them, at least might notice something like that. And, and I hope they do because that's going to be an amazing thing to be able to iterate to somebody in a conversation.

#### Bill Gasiamis 37:56

And to specifically know, hey, I know it's hard, and it sucks, and you hate it right now for some people. But if you do this, you'll notice these types of improved improvements are what other people have reported. the, with physical activity.

#### Dr. Kate Scrivener 38:14

Yeah, we've started in Sydney this week. So it's been a great week to meet the group of stroke survivors who are participating in Sydney and have come in for their assessments. And I'm they're selecting to participate. But they're all so open to the idea of the three-week, you know, 45-hour program and just giving it a go.

#### Dr. Kate Scrivener 38:42

Some are very confident they'll be able to do it and, you know, have access to some pretty intensive therapy now or in the past, some are not sure but are so committed to giving it a go. And, you know, that's, we're very grateful for that because that helps us to answer this question within the research.

# Emotional, physical, and psychological support after the High-Dose Physiotherapy

#### Bill Gasiamis 39:05

I know with research and funding for research, there are very strict parameters in which you can operate. And I get it. I'm wondering though, if some of the stroke survivors that I've met, will go through the process of giving themselves a timeline and deadline and be overconfident in their abilities.

#### Bill Gasiamis 39:22

And then they won't meet that deadline or hit that particular personal goal and it'll affect them negatively, psychologically, and emotionally. Is there any part of your study that kind of enables you to support people after the study or the project ends if they kind of take a little bit of a downturn emotionally or physically or actually, psychologically as well?

#### Dr. Kate Scrivener 39:53

Oh, Bill, I hope that won't happen. So, for anyone who's in the program, we will follow them up for six months. And for the people who are in so, there are two groups. Because it's a trial, there's the group that will participate in the high walk program, and there is a control group or a group that will do their usual activities.

#### Dr. Kate Scrivener 40:20

For the group that participates in the program, I guess we're at that stage where

we're not expecting anything negative to happen. But, if it does, or if they're demotivated, we will deal with that, within the parameters kind of that we can in the research, probably the trickiest part is most people are signing up because they're keen to try this kind of program.

#### Dr. Kate Scrivener 40:51

And if they are allocated to the control group, they're a little bit disappointed. We are, I will say, you know, we are not stalking anyone doing any of their usual exercise or therapies. And at the end of the six months, we do offer that group kind of access to the program.

#### Dr. Kate Scrivener 41:12

So it's only one session, but we'll still go through the program with them, and give them some resources to try that program at home if they wish to. So we are just very clear to people if they are going to participate that, you know, there is a 50-50 chance of trying the program or not.

#### Bill Gasiamis 41:36

I like it, okay, now, the reason I asked is because I just experienced being able to sort of facilitate people through stroke recovery as a stroke recovery coach, for example. And then some other people came to me after that stage when they thought they were further along in their recovery. And then they found they weren't, and they just took a negative view to it thinking that that meant that, you know, things were not going to be great from now on, which is not true.

#### Bill Gasiamis 42:11

And then it's like working with them, to make them feel like well, you know, deadlines, and that kind of stuff. They're not useful for anything, a hard deadline, especially that in 12 months, I'm going to achieve X is setting people up for failure.

#### Bill Gasiamis 42:27

Not that you shouldn't have a goal but I think the date should be flexible. And to say that it must happen by January 1, 2024. is setting people up for a potentially negative experience. If they've set their sights on something. They've got their heart set on it. Everything is set for that date, and then they don't get there.

#### Dr. Kate Scrivener 42:50

Yeah, I love that. Because maybe I need to make that clear because it is a three-

week program. But do we expect everyone to change in those exact three weeks? Probably not in fact, it might spur them on to positive things in the weeks, and months afterward, which is why we are following them kind of along the way.

#### Bill Gasiamis 43:17

So that'd be lovely to learn as well. So did it create a foundation for them and give them boosting confidence? And then as a result of that, did they find their path toward going to the gym for example? Did they sign up for the gym? Or do they meet a walking club? Or what did they do that happened after that would be amazing information for you guys to discover after the initial exercise program was completed. So is this a multi-site study that's occurring?

#### Dr. Kate Scrivener 43:52

That's right. Yes. So we have two sites at the moment, one in Sydney and one in Melbourne. As I said, we're running in Sydney, literally right now. And then we start at the Melbourne site in the first week of August this year.

#### Bill Gasiamis 44:10

And how's the recruitment process going? Have you filled the crowds, the numbers that you need for the study?

#### Dr. Kate Scrivener 44:17

We have almost filled the study in Sydney. We are recruiting very well in Sydney. We still have places available for the Melbourne booster starting in August. So if anyone is listening from Melbourne, we are very interested in hearing from you if you think you might like to be involved in this research opportunity.

#### Bill Gasiamis 44:41

I'm very familiar with the Stroke Foundation. I've done a lot of volunteering for them over the years. And although it's probably been since COVID, that I've been not as active as I used to be. I was just curious about how they're involved with the program other than funding it. What happens when somebody says to you "Here's some money, run your research program" And then what do they do? How do they sort of stay in the loop? Do they? I know the stroke foundation wants to be in the loop because that's their key criteria are to help people overcome a stroke and to support people with stroke deficits, how do they specifically get involved and stay involved?

#### Dr. Kate Scrivener 45:25

They are very supportive. And even with things like trying to notify the stroke community, that this opportunity is available, they will work with us for that. But really, they give me the money to do the work, and then I'm accountable to show them you know, what we were able to achieve and answer with the research. And I need to do that. And show them hopefully, that they've got good value for money out of this project.

#### Bill Gasiamis 46:00

Well, they're gonna learn something either way, and it'll be good value. So is there someone that you deal with in this space in the Stroke Foundation? Is there somebody that sits in a room that does this job with researchers that they've supplied with funding?

#### Dr. Kate Scrivener 46:21

That's right, yeah. So they have a research office and very lovely people who support us along the journey, once we do get the funding.

#### Bill Gasiamis 46:31

Yeah. Brilliant. So there's a whole community coming together to support this project? To find out one way or another, some answers as to whether or not this particular what do we call it? High Dose program is going to have outcomes, and then those outcomes do these studies then become other studies? Or do they kind of pause?

#### Bill Gasiamis 47:01

What happens once you have completed your study, you have reported it, and you've told people what the outcomes are? I imagine it will hopefully published somewhere with your findings. Tell me about that phase of the program.

#### Dr. Kate Scrivener 47:14

Yeah, that's exactly right. So you want whatever we find, we want to make sure that that's out there for stroke researchers and clinicians. So we would try and publish the results. This is, you know, one of the steps and I guess whether it goes anywhere after this depends on what we find, you know, what we need to know is that this bigger group of stroke survivors, what do they think of this kind of training?

#### Dr. Kate Scrivener 47:48

Does this kind of training meet their needs? Or not? Do they participate in it?

What does it do to the rest of their life, then we'd like to see a hint that this program is effective in improving their walking.

#### Dr. Kate Scrivener 48:09

So I guess until we know, how successful it is, know, the outcomes will either it will perhaps stop there, and we'll have to rethink or if it is successful, we'll refine the program based on what we find and the stroke survivor's experiences. And then we'll try to, investigate the program in an even bigger study, to know the effectiveness of this kind of program. And to understand how that effect changes or tracks over time.

#### Bill Gasiamis 48:50

One of the criticisms, criticisms of science-based research projects is the amount of time it takes A for this study to occur. I mean, it's all understandable. But this is kind of one of the criticisms that I've sort of become aware of the time that it takes A to create the study, raise the money, do the study, and report on the outcomes of the findings of the study.

### The next phase after the study

#### Bill Gasiamis 49:13

And then the applications of the study. What happens is that we have the outcome that we desire, a positive outcome, and people love it. And now you've got a tool that's proven scientifically, to create better outcomes for stroke survivors in walking and not tripping over. How, does that become then applied to the physiotherapy field? Is there a quick path to application or how does that happen? What's the next stage like?

#### Dr. Kate Scrivener 49:55

I love your idea. I love your positivity that we're going to find that it works. If it does work. The nice thing about this is it is really like it is a set program. And there are guidelines and resources already about how to conduct the program because we're starting next week in Sydney.

#### Dr. Kate Scrivener 50:14

So if we do find it so effective, the plan is to make all of those resources freely available to physiotherapists. So if they want to run the program, they can run it. I know it is, look, the time from research to clinical practice is long. The challenge

is with something like this where it is a real shift in clinical practice, it's a different way of doing something.

#### Dr. Kate Scrivener 50:46

It is hard to do that unless you have the research behind you. And we don't know that this is the right model yet. You know, we do need to refine it. With the research. I hope we're on to something or at least on the right track. We're going to find out.

#### Bill Gasiamis 51:09

Yeah, my instinct tells me that you are my experience tells me that you are my conversations with other stroke survivors who, "fall through the gaps" and then end up with a little physical therapy says that you're onto something. And specifically, what that something is, is I think going to be positive, but how positive and what exactly data you get out of it, that's going to be the exciting part.

#### Bill Gasiamis 51:39

To determine what the data says, as opposed to what say, even if it's 10, very, just very broad conversations that I've had about it with people which are anecdotal, but still positive, in that the more physical therapy they get, the better the outcome.

#### Bill Gasiamis 52:00

And I just know that in that space in the recovery from stroke space, if the people are not suffering with debilitating fatigue, because of the deficits, and they are seeing that decrease of fatigue, and the increase in the sustainability of exercise and fitness level and all that kind of stuff, I just know that that's having a positive impact on the brain in every way, shape, or form.

#### Bill Gasiamis 52:32

So I believe that you are going to get some amazing results out of it. And we will learn a lot from it. And that's the reason why I thought, you know, when you reached out and you say to me, can we promote this, I'm all for it. And I think we need to get as many people as possible in it because that's what my community is telling me. They're telling me that that's where they're struggling to get resources.

#### Bill Gasiamis 52:57

And if a physiotherapist in the local area gets access to the results of this study, then can implement it locally. That will be even better, because some of the challenges that stroke survivors face is accessing resources locally, and they need to go from a one-hour travel every day. And that adds to the three hours and then one hour travel back. And then that becomes a real issue. So I like everything about this study. Hopefully, my questions are reasonable.

#### Dr. Kate Scrivener 53:34

You've got great ideas, Bill. I mean, for me, the long-term dream is there's almost, I don't know where these places you can go. But if you're a stroke survivor, and you're saying my walking, I'll use walking as an example, it could be anything, let's say it's walking, my walking needs a boost. There'd be a place to just self-select, and go and do the program.

#### Dr. Kate Scrivener 54:00

I'd love it to be free. But you know, we'll work that out. Let's say that it works first. If we can get the duration and the dose right to suit stroke survivors, we know that if they went for this boost, it would improve their walking. I just think that'd be great.

#### Dr. Kate Scrivener 54:24

And then imagine if in six months, 12 months, two years, whenever you needed it again, you could go and self-select again. That's kind of the idea. Could you have access to a short-term boost when you need it?

### The Recruitment Process in Melbourne Australia

#### Bill Gasiamis 54:39

Yes. I love it. Let's talk a little bit about the recruitment process in Melbourne. What's the best way for people who are in Melbourne to get on board with this program?

#### Dr. Kate Scrivener 54:56

so there's a trial phone number and then there's The same email address, which is my email address, so you can email me, and let me know that you're interested. And typically, we'll send you some information, or have a chat with you over the phone and just tell you a little bit more specifically about what's involved and what the commitment would be from you. And then there's absolutely no

pressure, you get to think about it and see if it is something that you'd like to be involved with.

#### Bill Gasiamis 55:28

The location where this is all going to take place is Melbourne. Do you know where that's located?

#### Dr. Kate Scrivener 55:33

So it's actually in Tarneit. And I say it that way because I think it's not speaking to other researchers in Melbourne. It's not a typical research site. But I know that there are many stroke survivors in the west of Melbourne down to the Werribee Geelong area.

#### Dr. Kate Scrivener 55:56

So I'm hoping that it's an attractive thing for people who are in the west of Melbourne. Though we won't limit we definitely won't limit it. We have people who are coming, to see us for the program. And I think we might have one or two people who have agreed to cross Melbourne and come over to the west to be part of the research as well.

#### Bill Gasiamis 56:22

Fantastic. Well, that's good. Well, I appreciate you reaching out. And thank you for chatting with me about this project and program. I would love to know the outcome of the research when the time's right. And I wish you all the best with it.

#### Dr. Kate Scrivener 56:41

Thank you so much, Bill. I appreciate your time and positivity about the research and I will keep you updated with the results.

#### Bill Gasiamis 56:51

Well, thank you for joining me on today's episode 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 recovery after stroke.com/episodes. If you'd like to support this podcast, 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 57:16

If you're watching on YouTube comment below the video I look forward to receiving comments, and I love responding to all people who comment on my

videos like this episode to get notifications of future episodes, subscribe to the show on the platform of your choice. If you are a stroke survivor with a story to share about your experience, come and join me on the show.

#### Bill Gasiamis 57:40

The interviews are not scripted, you do not have to plan for them. All you need to do to qualify is be a stroke survivor or care for someone who is a stroke survivor. Or like Kate work in a field that supports stroke survivors go to recoveryafterstroke.com/contact fill out the contact form and as soon as I receive your request, I will respond with more details on how you can choose a time that works for you and me to meet over zoom. Thanks again for being here and listening. I appreciate you see you on the next episode.

#### Intro 58:12

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#### Intro 59:36

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