

Jenny Clarke's Vision for a Brighter Future for Brain Injury Recovery - SameYou.org

Jenny Clarke together with her daughter Emilia Clarke are the founders of the charitable organization SameYou.org, a non-profit that supports young adults who have suffered from brain injuries, including stroke.

Website

Youtube Channel

The Untold Story

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Jenny Clarke 00:00

What you said is you wanted to take back control. And I think that is such a fascinating topic in itself. Because what you highlighted was that you felt that you weren't in control the others were in control of your recovery. And I think that so many people say that to us, but it's sort of infantilizing people. So it's taking away your adulthood, your urgency about yourself.

Intro 00:32

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

navigate recovery after stroke.

Introduction



Bill Gasiamis 00:45

Hello, and welcome once again to the Recovery after Stroke podcast. This is episode 238. My guest today is Jenny Clark, who together with her daughter Emilia Clarke co-founded the charitable organization, Same You.

Bill Gasiamis 00:59

Same You is a nonprofit organization dedicated to improving access to neurological rehabilitation for adults, particularly those recovering from brain injuries and strokes. Emilia Clarke is an actress best known for her role as Daenerys Targaryen on the television series, Game of Thrones.

Bill Gasiamis 01:18

Through Same You, Jenny and Emilia aim to raise awareness of the challenges faced by young adults in accessing neurological rehabilitation and to provide support and resources to those in need. Jenny Clark, welcome to the podcast.

Jenny Clarke 01:34

Thank you so much, Bill. It's a privilege and honor and I'm excited to find out what it's going to be like,

Bill Gasiamis 01:40

it's gonna be fun. We're going to have a good time. I reached out to Same You via

the Instagram page. Because sometimes when you don't know how else to connect with somebody in an organization like Same You, and you love the work they do.

Bill Gasiamis 01:58

You just go the quickest route. So I did that. And I said, Hey, is it possible for me to interview with Emilia Clarke? And of course, they said, look, Emilia is busy. It's not possible. And then I didn't think to say A. What about somebody else from Same You?

Bill Gasiamis 02:17

And a little while later, literally a few months later, I received an email from the amazing Veronique, and Veronique said, Hey, would you love to have Jenny Clarke on the podcast, the founder of Same You? And I said, of course, I would. Therefore, I fulfilled my goal of connecting with you guys and getting you on my podcasts, so I can share the work that you do because I love the work you do. I don't like the way you got to doing the work that you do. So I'm wondering, though, if you could share a little bit about the journey that got you guys to be in this space right now?

How Emilia Clarke's Stroke Journey Began



Jenny Clarke 03:00

No, thank you for that. So we were just completely unaware oblivious, of any issues that you might have with your brain until Emilia had her first brain

hemorrhage. And that was just after she finished filming the first season of Game of Thrones, which was pretty traumatic for somebody just out of drama school.

Jenny Clarke 03:00

And we don't know why it happened. She was actually at the gym, doing the plank when the brain hemorrhage happened. So she was super fit, super young, early 20s, which is what saved her life. So the issue that we first found, which I can go into later, was it interestingly, it's very difficult to have general doctors diagnose brain hemorrhages.

Jenny Clarke 03:59

But when she was diagnosed and was treated, and we realized everything was fine, took a long time to realize that. We knew that she had a second mirror aneurysm. So two years later, she was on Broadway, and she went to have preventative surgery. And the US system is very different from the UK system. And we believed that we really could trust them to coil a very small aneurysm.

Jenny Clarke 04:30

And it didn't work. It went very badly wrong, no fault on anybody because these things happen because it's so sensitive and friable. So she had a very, very serious couple of strokes open-head surgery fighting for her life.

Jenny Clarke 04:46

And then, despite everybody saying, Oh, she's gonna lose this, he's gonna lose that she's gonna be whatever she isn't and wasn't. And so the result is that she has clinical fatigue, which she has to manage, that doesn't go away.

Jenny Clarke 05:04

But that's about it. And you know, twice, and these near-death experiences, we just thought, Well, my goodness, we, you know, she has a platform, maybe if she did start to tell people about what happened to her, she could help normalize it in some way.

Jenny Clarke 05:22

Because we saw straight away that there was such little provision for helping people get their lives back after a brain injury or stroke. And because she was in her 20s, both times it is obviously, clear that when you're young, and maybe haven't quite got your identity together yet, whatever that might be.

Jenny Clarke 05:47

And then something catastrophic happens. And it's your brain, which is, you know, arguably, you. And you haven't got help, whether it's physical, psychological, cognitive, speech, or language, whatever the things are, that you need, you need mental health support. Just really, in most countries, it's patchy, or it doesn't exist. So we just thought, let's try and do something. So that's how we started.

Bill Gasiamis 06:25

Was Emilia in the UK, or the US, for the majority of her, we'll call it treatment or recovery?

Jenny Clarke 06:37

The first time she was completely in the UK. And so the wonderful NHS gave us. Intravenous paracetamol, we like that. In the US, she was given a cocktail medley of terrible drugs, we don't like that. And so that was all obviously about pain management at the beginning. But in terms of recovery, there was none offered in either country.

Bill Gasiamis 07:05

So you're not saying anything that's not familiar to me, this is the weird part, you're talking about the American system and the British system. In Australia, it's not that different. So my journey was in 2012. So around the same kind of base in time when nothing existed online to get support when I went home after the first bleed in my head, and it was just sick, go home, sit and wait it out for six weeks.

Bill Gasiamis 07:33

And then what we'll do is we'll reassess in six weeks when things have settled down, hopefully. And then it's like, okay, so six weeks, almost to the day that I was supposed to be back in hospital for my follow-up, I had another bleed. And then it was pretty catastrophic in that the size of the clot that was in my head started as what I would call the size of your large fingernail.

Bill Gasiamis 08:00

And then it became about the size of a golf ball. And which meant that it was impacting way more of the brain. And I went home with cognitive deficits, that were so dramatic that I didn't know how to start a sentence sometimes finish a sentence, I would forget about who came to visit me. I was aggressive and angry.

Bill Gasiamis 08:23

I had a whole bunch of issues relating to trying to make my brain calculate things and work out things. And my working memory was terrible. There's a whole bunch of issues, right? And just by habit, I had been seeing a counselor for many, many years before my first bleed. So, I think by then I would have been on that counseling journey for about 12 years.

Bill Gasiamis 08:52

It's just something that I've always done. And when I got to my first appointment, after the second brain injury, and I had a conversation with my counselor, my psychologist about what had happened to me, she must have noticed a massive difference. And she's the one who said, have you ever had anyone booking a neuro-psych assessment so that they can determine what your deficits are so that they can provide you with some support to help you navigate those deficits and do some work to potentially improve those deficits?

Bill Gasiamis 09:31

I said no, no one's ever told me that I didn't even know what a neuropsychologist is. So on that information, we went through the public system here in Australia, and I made a booking for an appointment with a neuropsychologist, but the earliest booking that I could have was nine months later.

Bill Gasiamis 09:55

And I didn't realize that because my brain wasn't working properly and my wife was in all sorts, I didn't realize that nine months was nine months away and that it was such a long time away. And by the time I eventually got to nine months, a lot of the deficits had decreased on their own and gone away. But we hadn't done anything to do that. It was just a natural progression of the brain kind of dealing with or getting used to the blood clot. And as it decreased in size because it was being absorbed by the body or being broken down.

The Five Foods To Avoid After A Stroke

Bill Gasiamis 10:35

A lot of my deficits just came back online. Hi, everyone, just a quick break and we'll be right back to the interview. As a stroke survivor, I understand the difficulties of finding the right information about post-stroke nutrition. So I

developed a course on the five foods to avoid after a stroke.

Bill Gasiamis 10:52

Most people are talking about what to eat after a stroke to support brain health and recovery. Very few are talking about what you should avoid eating after a stroke. If you want to support your brain to heal, and you are curious about the five foods that may make matters worse, when you consume them, then this course may be for you.

Bill Gasiamis 11:12

In the Fun Five Series of interviews, you'll hear about what foods not to eat after a stroke. But most importantly, why the interviews are done with a qualified nutritionist Stacy Turner, and performance coach Matthias Turner? In the more than five hours of interviews, we discussed the five common foods that cause inflammation in the body and brain how they could interfere with healing, and how they could make fatigue worse.

Bill Gasiamis 11:41

For just \$49 this five-part series of more than eight hours of interviews with full PDF transcripts mp3 and videos will give you everything you need to know about the foods to avoid and why, the modules include Eight reasons to quit sugar after stroke, Seven reasons to quit caffeine after stroke, Eight reasons to quit gluten after stroke, Six reasons to quit dairy after stroke, and Six reasons to quit alcohol after stroke.

Bill Gasiamis 12:11

So visit recoveryafterstroke.com/courses. For this and other specifically designed courses that are made by a stroke survivor for stroke survivors. Once again, you will get more than eight hours of content. All audio is downloadable in mp3 format, so you can listen on the go. full transcripts of all the content to take notes on are available for download so that you can read instead of listen.

Bill Gasiamis 12:41

Presented by a stroke survivor for stroke survivors. also presented by a trained nutritionist and performance coach, you'll get 24-hour access, lifetime access to the courses purchased and you'll be able to interact with me in the comment section. Go to recoveryafterstroke.com and check them out now.

Bill Gasiamis 13:00

Of course, it wasn't dealing with just that. Like you guys, we were dealing with all the unknowns, all the uncertainties, all the emotional trauma, trauma. Well, the psychological trauma.

Bill Gasiamis 13:12

And then the lack of guidance at home meant that every time something weird happened to me or I felt strange or I wasn't feeling well, we were always wondering, oh my gosh, is this another one? What do we do? Always second-guessing ourselves, never feeling comfortable with any decision that we made about how we should proceed going forward.

Bill Gasiamis 13:43

And it meant the endless amount of unnecessary in hindsight visits to the hospital, to wait again in waiting rooms to get assessed and reassessed to have more MRIs, more CT scans, and so on to see what was happening. So that we share in common.

Jenny Clarke 14:07

Yeah, and I think we share that in common with millions. And what we think, you know, after this journey of actually launching the charity, four years ago, in March next month, what we've learned is astounding, that this is such a prevalent problem. And it's an emergency problem it's always catastrophic and traumatic.

Jenny Clarke 14:31

Whether you have a stroke or anything else that happens organically in your brain, or you have some sort of an accident, sports or road traffic, whatever, it makes it a brain trauma. It is just so catastrophic for people and their families and their friends and their workplaces and the health service because everything you've just described so eloquently has such a major economic impact and knock-on with readmissions.

Jenny Clarke 15:05

Preventing people from getting back to work getting back to school and getting on with their lives. So it just still is extraordinary that this is not a topic that everybody is hotly debating, and trying to fix. I mean, I know the world is burning, and we have so many problems. But this is a severe problem that isn't hitting the radar.

Bill Gasiamis 15:29

Yeah, the world's always been burning, and not only has always been burning, but I'm somehow in that state in that situation. There's been amazing progress forward to raise awareness about prostate cancer for men, breast cancer for women, among the many other amazing things that we have awareness about now, ALS, or Lou Gehrig's disease, or Alzheimer's or all those things, whatever they are, and when the stats are now I think they've been revised that one in four people will experience a stroke in their lifetime.

Bill Gasiamis 16:07

We in Australia still struggle to have people be aware of what a stroke is, what it looks like when somebody is having a stroke, and what to do. If you are with somebody that's having a stroke. And still, stroke survivors often tell me they went to hospital.

Bill Gasiamis 16:26

And if they went on a wrong day, Friday evening, or Saturday evening, they were often told to take a seat because they were probably drunk or probably taken some drugs or did something like that. And then they did what they were told, and that made the situation and matters worse.

Jenny Clarke 16:47

Indeed, exactly. And in fact, we say put if we call it acquired brain injury, which is the clinical term for a stroke, or traumatic brain injury, so anything that isn't generative, and anything that hasn't happened at birth to you, any other brain injury is called an ABI acquired brain injury. And that we reckon with UCLH. In London, that's one in three people. So it's astounding. So yeah, I think there is so much to be done. And I think one of the hard things when you've got such a large problem is knowing where to start.

Discovering The Stroke Community

Bill Gasiamis 17:29

Yeah. And it sounds like that's what motivated you. But that's what motivated me to do what I'm doing. So in 2017, I thought well, it was actually in 2015, I thought, well, I've got to somehow find a community for myself. So it was kind of like a selfish thing. At the beginning. It was like finding a community for myself, to feel better about everything that I was going through and still had to come.

Bill Gasiamis 18:01

And I thought, Well, I'll start interviewing people that I think are inspiring, who have overcome really serious health issues. So that I can, you know, have some role models and feel good about the possibility of my recovery and moving on from this situation. And that led to a podcast that wasn't called the Recovery after Stroke podcast that was called.

Bill Gasiamis 18:29

Well, such a while ago, I forgot what it was called. And, as a result, I got so overwhelmed by the responses from people and the fact that I was being contacted every so often being told that that episode was necessary for that episode I relate to and thank you for this episode. And the rest of it, I realized I was onto something.

Bill Gasiamis 18:58

And I realized that what I was onto was the thing that I was missing when I was going through this because we had nothing we had just me and my wife and frequent communication with our doctors who spoke in medical speak anyway. And the only thing that I could speak to was the part of your journey that started in the hospital, and then that ended in the hospital, and then they weren't able to speak to anything that came after that.

Bill Gasiamis 19:28

So I felt like I needed to do this for me, but then I realized that it's doing a massive thing for other people. And that was unexpected. I didn't realize in my state that that would be the case. Before we get to speaking about Same You and how you guys got to come up with the idea develop it and create the charity I want to get a bit of a sense of what it was like for you to go through the diagnosis and the hospitalization of your daughter.

Jenny Clarke 20:13

So I think parents everywhere understand that when you have a child in their early 20s, they're still a child to you. They might believe that they are, you know, world-beating professionals, but there is still such a strong bond. But you've gone through the whole process of leaving home university, drama school, whatever living away all of that stuff. And then you something you know, you always, again, a parent dreads getting a phone call, my phone is on 24/7 because I've got two kids.

Jenny Clarke 20:55

No other reason. Because you always think what if something happens, and so with my son, something happened earlier, which was, again, not good. But that's all been managed. And then when we got the call for Emilia so I think that my reaction was one of complete terror. And it was, in fact, a New Zealand neuroradiographer who saved her the first time when I say saved her, effectively put a coil into her bleeding aneurysm that blocked it, and prevented a further stroke.

Jenny Clarke 21:37

And he did it very well. And it's a great art. And so we were so lucky that we weren't we managed, I fought to get her into the best place in the UK in London. And that's called the National Hospital. And colloquially known as Queen's Square, because that's a place that it's in. It's an old hospital, it's linked to UCLH. And it's somehow separate from it because it focuses on diseases and emergencies of the brain.

Jenny Clarke 22:09

So it was it was horrendous, it was the worst possible, you know, thought that I could have, because we didn't know if she'd live or die. And going through that. That was pretty terrible. So but you know, it's all about taking action, doing something not sitting passively. So I was one of those annoying women, really bugging the doctors every step of the way to find out what was happening.

Jenny Clarke 22:36

And to see what else they could do, and to just, you know, use my will to try and make her survive. And then we found out later, two years later, that I've got aneurysms, because the first thing they say to you, when did they discover you've got an aneurysm, is there anything in the family any familial experiences? And we said, no, no, not at all. And so I've now got three aneurysms.

Jenny Clarke 23:05

So the same as Emilia to mirror an aneurysm, one life had coiled as an emergency, which I didn't know about, just by accident, I had a brain scan. And then I've got two other smaller ones. So that relates not just to Same You, but it relates to, you know, really quite a broad understanding of the issue of actually living with something like a time bomb ticking in your head. And how do you deal with that?

Intro 23:37

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. 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. But, if you've never had a stroke before, you probably don't know what questions to ask.

Intro 24:01

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

Intro 24:20

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

Jenny Clarke 24:40

And what that can mean and the impact it has on everyone's mental health. But yeah, to answer your question, it was the worst possible experience I could ever have. Apart from losing her course.

Bill Gasiamis 24:53

Yeah, yeah. Thank God, that it didn't end that way. Now, I so often wonder what my parents thought, and I haven't been able to have that conversation with them. It's been this February will be 11 years, since the first instance. Now I know that they fell apart.

Bill Gasiamis 25:17

Personally, each of them fell apart differently, because of the way that they responded, I could just tell that they weren't able to manage the situation and the gravity of the situation. But I've never actually sat down to have a chat with them about that. And it's very interesting for me to hear your response to what it was like for you because I'm a dad, I have a 22-year-old and a 26-year-old, you know, I can only imagine.

Jenny Clarke 25:50

Wow what's your skincare, tell me.

Bill Gasiamis 25:54

It's called being young and dumb, and getting married way too early. And started a family before I had planned it, but I wouldn't change it for the world. And everything I did, has just worked out beautifully. And it's amazing. And it's fantastic.

Bill Gasiamis 26:11

And I'm 48 and it's such a great time to have my kids around me because they are adults now. And we, in my early middle age, we have, you know, have an amazing connection and relationship. So I cannot imagine what it's like to go through what you went through.

Bill Gasiamis 26:35

And at the same time knowing that material event arteriovenous malformations are sometimes potentially, in families, they run in the family. And discovered that my cousin in Greece, my dad's niece also has an arteriovenous malformation that is causing her some drama like epilepsy, etc.

Bill Gasiamis 27:02

It puts me in that situation where I don't know whether what I should tell my kids is to go and get their heads scanned or not. If we find that they get the head scan, and there's something there, then what do we do with that ticking time bomb, so to speak all that information?

Bill Gasiamis 27:18

And then if we don't do anything, you know, then do we just sort of bury our head in the sand and pretend that everything's okay when it could well and truly be okay, but it may not. So this is kind of what's troubling me about my journey. And then having kids that are, you know, vulnerable to life as well. And then me dealing with my mortality, and then somehow, maybe sometimes even superimposing that potential mortality onto other beings that you love that around you. It's just, sometimes it's troubling to think about it and contemplate it.

The Importance of Getting Access To

Brain Scans - Jenny Clarke

Jenny Clarke 28:04

No, I understand what you mean completely. Because I talked to many doctors, neurosurgeons, neuro neurointerventionists. And many people, many of them have said to me, because there is the tricky question of do people have brain scans, because the only way you're going to find out if there's anything in your brain that has a potential of imploding or exploding or whatever way you want to describe it?

Jenny Clarke 28:37

If you can't do anything about it, why alert people? So that's, I think, maybe received wisdom in the UK from the established clinicians. But I think that while applauding them being internally grateful, and understanding what huge a training a neuro anything has to go through, and what would we be without them? The whole point is that medicine today is science-based completely.

Jenny Clarke 29:12

So everything has got to be evidenced. And there is a very gray area in my experience, about what evidence is. And so medical establishments are in charge of our lives. And obviously, they need to be as sure as they possibly can. And I think that there's got to be a revolution which I see happening all over the world, where there is much more of a balance between the scientific approach and the ancient emotional approach.

Jenny Clarke 29:45

So I'm not being in any way, talking about alternatives. I'm talking about the growth and development of the science of medicine. And I think through broadening it and broadening everybody's perceptions of how people can be helped. I'm my I would love to say healed, because recovery, which is the focus for our charity is about healing. And on so many levels, people can be healed.

Jenny Clarke 30:19

They may not be healed completely, they might always live a life that they didn't expect to live. But we call the charity Same You, because we're all the same, whatever catastrophe happens to us, inside we are the same. And it's really hard to fight for your identity to be acknowledged by people that you know or people who you just met. And so I think it's vital for everyone to know who they are.

Jenny Clarke 30:53

But that's a bit of a digression. But to go back to your question, or maybe it wasn't a question a rhetorical question, giving me your experience, I think that people should investigate and know because using a very strong cliché, knowledge is power. But if you are of a very anxious disposition, naturally, and people are, it is questionable whether you're an anxious person with fearfulness about the world and life, that will just make things worse for you.

Jenny Clarke 31:34

On balance, I think people should know, but then you've got the question of how expensive it is to be scanned and how it's not in any health service, which is all a failing around the world. It's very difficult. So it's a very deep and complicated question.

Bill Gasiamis 31:50

Yeah, again, I never know how to phrase this, I had the pleasure of interviewing a lady who lost her daughter to an arteriovenous malformation when the child was five years old. And she's again, also moved to do something about the situation that she found herself in and then doing something to prevent it happening to other people. And one of the things that she's advocating for in the United States, is free brain scans for people.

Bill Gasiamis 32:34

And they going around, and while I'm talking, I'm just trying to look it up on my website to find the episode. So I can tell people about it in case they want to go back and listen to it. And, they are in the process of raising enough funds to create to set up a clinic where they have their machine that is supported by doctors I imagine, and radiographers who are qualified to evaluate such scans.

Bill Gasiamis 33:08

And then from there, their goal is to basically for people who want to know to give them the information so that they at least have a chance at potentially doing something about it if they choose. And again I found myself conflicted in the interview. Not at all, the work that she's doing amazing work, there's tireless work that she's doing while dealing with the challenges of losing a child.

Bill Gasiamis 33:56

But then, with the idea of what do you do with that information? You know, how

do you move forward with that information, especially if your child is young? But she assures me that there would if she had known, they would have done something about it. She says that in hindsight, I know that she says it in hindsight, but they would have done something about it and to be robbed of her child the way that she was robbed of a child at school, in class around her classmates, and then to get the phone call that they got.

Bill Gasiamis 34:40

It's why wouldn't that person want to go out of their way to find other ticking time bombs in other people's heads and tell people about it and say, hey, you've got this, maybe you should take some action, or at least you should know about it. And I'm not normally somebody who struggles to talk on my podcast, get words out make sentences, or put sensors together.

Bill Gasiamis 35:06

But this bothers me, this is a real struggle for me to come to terms with because I'm as a father, struggling with that idea. And then I've had plenty of interviews with people that have been through it like you and, and other people. And it's, and it's just, you're damned if you do and you're damned if you don't it's a situation of that.

There Is Prevention In Recovery

Jenny Clarke 35:34

No, it is. And then there's, you got the two critical words, I think prevention and recovery. And we focus on recovery. But in reality, there is prevention within recovery. And what I mean by that is if people have got support and are treated in the best possible way.

Jenny Clarke 36:04

And having access to recovery, and rehabilitation services, whether it's from clinicians, from therapists, from peers, or self-help, you do prevent people from getting ill again, from having another crisis. And I think that the concept of being armed with information that they you have, potentially life-threatening issue somehow feels that it's very important for people to have that choice of knowing.

Bill Gasiamis 36:43

Yeah, I feel like I agree with you. And there's a sense of a little bit of control

where otherwise control is taken away from you, it's put in the hands of other people. And, at least in this way, you're partly in control of your destiny, and you make it a really good outcome. And if you don't, at least, it's a path that you took under your own steam.

Bill Gasiamis 37:08

And therefore, for me, at least, it would give me some feeling of not being out in the wilderness and not waiting for supposedly fate to take its course, it'd be an intervention that I could take and, and, do something about being that my kids are adults. It's their decision.

Jenny Clarke 37:42

But you're there to guide them even if they're adults. So I think that what we see from all the thousands of people who've written to us is that you've got on the one hand, you know, the group of people who have gone through this problem, and they tell us their needs and wants. And then you've got, on the other hand, the amazing clinicians who are not a bad word to say about them.

Jenny Clarke 38:12

But then if you see that they're not like this, there is a very, very big gap between what people want and need and what clinicians believe that they can offer, or that people should have. So I think that one of the things that has got to change in the next years is this coming together of that dynamic, where you've got a much, much more open dialogue, and multitude of services that don't currently exist in an organized way.

Jenny Clarke 38:50

Many services do exist. And fantastic. And they might be small, they might be unproven. And they're the first, so in, you know, in universal health care, you always have to have something with a systematic approach. So I think that what we're trying to do is to see if we can find ways of understanding what these new advances are, and understanding what could be possible with trying to find pilots and funding some ways to test different interventions. So I think that is the future for me. And that also, obviously, has to do with prevention as well as recovery.

Bill Gasiamis 39:37

And we'll get into talking about the same you in a moment, more deeply, but as part of that thing that you guys do is it also creating an easy path to access those

services for people that have had a stroke?

Jenny Clarke 39:54

We would love to be able to I don't think that it's in our power to do that but it's about accessibility. So what we see is that wherever you might be, there are so many levels of severity of brain injury. In the UK, it's a very complex NHS hierarchy. And if you have got a severe severe brain injury, there are places to go.

Jenny Clarke 40:23

And you get automatic post-discharge, or, inpatient rehab, and then post-discharge help. But it is quite, depending on the severity, it's finite. And usually, and it's the same in the States, you know, it's four weeks, 12 weeks, 16 weeks, and we talk to people in 10 years after they've had their stroke or brain injury, and they're still not in one piece, again, when they could be helped to be putting their pieces together.

Jenny Clarke 40:54

And living fulfilling lives in a much more easy way and a much easier way. And so that is such an issue. And so accessibility is one thing, and innovation is another. So what we still do as a, I call us a startup charity, you know when coming into our fourth year, we still are trying to figure out, what is the best approach for us to take. Because we don't have ambitions to be you know, anything that's got a lot of overhead, that is an organization.

Jenny Clarke 41:37

Because I think that is there's plenty of people doing that. And they're not moving the needle very much. And again, no criticism, but they do what they do. But they're just to me has to be a different way of approaching it that maybe could have more impact less conventionally.

Jenny Clarke 41:37

Organizationally, I mean, I don't mean, again, and don't mean alternative medicine, I mean, just structurally trying to solve problems in much more of a community a network of collaboration, as opposed to this 20th century in a large organization.

Bill Gasiamis 42:21

Yeah. And it feels to me that, at the moment, things are fragmented. Like you said, there are amazing service providers of those services, but accessing them in

a cohesive way that works for particular individuals, is challenging. For me, I had, you know, one appointment on this side of town, the other appointment on that side of town.

Bill Gasiamis 42:42

It was just difficult to navigate, and fit all those appointments in considering the condition I was in, the amount of time it took out of my day the fatigue that I was experiencing, and the resources that I had available to me and all those things, and it was just 1.3 appointments per week was just almost too many to get to.

Bill Gasiamis 43:08

I did get to the stage where I got my rehabilitation to a point where my walking improved enough that I told my therapists You guys are sacked I no longer will be coming to see you, you've done a great job, I'm taking the responsibility for the way that I walk myself now to myself, and I'm going to relieve you of that duty.

Bill Gasiamis 43:33

And that was because I couldn't handle the three-hour round trip that it took one hour to get there, and one hour to be there. And then one hour to get back in the middle of my week. It was just so disruptive to my week that I needed to stop going there.

Bill Gasiamis 43:51

And I didn't want to stop going there. Specifically, I wanted to put as much energy into my walking again as I could. But I just felt that I was better served doing that at home. Then allocating that much time of well, I'll call the travel time wasted time to be there for an hour, you had to go two-thirds of my time away. It was not in rehabilitation. It was a way of travel and I just thought it was nuts.

Bill Gasiamis 44:26

It wasn't an efficient use of my time. So I get it, I get what motivated you to put your heads together and come up with something to make a difference and I love I love that now just before we get onto the same younger, just let people know anyone interested in listening to Paige to Episode 141 it's about Gina Keeley and the foundation that she set up in the honor of her daughter Paige It's called the Paige Keeley foundation. So you can just go to recoveryafterstroke.com/episodes, scroll down, and you'll find episode 141. And you can have a bit of a listen to that story now.

Regaining Control In Your Recovery

Jenny Clarke 45:13

But can I just say that you were just framing something that I think has got to be highlighted, what you said is you wanted to take back control? And I think that is such a fascinating topic in itself. Because what you highlighted was that you felt that you weren't in control, the others were in control of your recovery.

Jenny Clarke 45:41

And I think that so many people say that to us. Because it takes me, I can't even pronounce the word, but it's sort of infantizing people. So it's taking away your adulthood. And your urgency about yourself. So I just at some stage, can we talk about that a little bit more? I think that's fascinating.

Bill Gasiamis 46:03

Yeah. Let's talk about that now. Because I've got time. For me so if I shed some more light on that, it's exactly that. It's the reason why I sacked my first neurologist, and team of doctors that were helping me after the second bleed. So what happened was, that I went in for the first bleed at the Austin hospital here in Melbourne, it's very close to home, and it's extremely convenient.

Bill Gasiamis 46:34

And when I went home and did my six weeks, as I was told, and then ended up back in hospital, I found that they were talking about me, at the end of my bed, but they weren't including me in the conversation. And as much as I tried to involve myself or get them to respond to my questions, I kind of almost got brushed off.

Bill Gasiamis 47:02

And I'm the kind of guy that I need information good, bad, or indifferent, I need to know everything about what's happening to me so that I can help inform the way forward. Because I don't feel comfortable with somebody going down the path of making decisions on my behalf from their version of the world.

Bill Gasiamis 47:23

And from the version of the world where they consider themselves or elevate themselves to the point of expert, which they are in medicine, but they're not in how I want my life to unfold and evolve. So I had a friend of mine, who was a

radiographer at the Royal Melbourne Hospital, which is inconveniently further away from home.

Bill Gasiamis 47:51

Nonetheless, the fact that he was there, I was able to ask him to put the word out for me and find a neurologist. And these are the words that I said to him who's going to talk to me? And he was able to find somebody willing to take on my case.

Bill Gasiamis 48:09

And that changed the course of my recovery, because from then on, even though she was the neurologist, and the person that was the expert at helping me stay alive, I felt like I was the one that was calling the shots. And I believe one foot wholeheartedly that I was because her approach was, tell me how you want to proceed. And my suggestion was, can we wait to not have brain surgery yet?

Bill Gasiamis 48:48

Are we at that stage where we can still wait? Or is it? Do we have to go in now? And she said, Look, we could probably wait. And to help you go down that path. Why don't we do monthly MRIs for the next six months, and see how everything is changing or pay to notice what differences there are so that we can make informed decisions rather than just immediately decide to go in and potentially, we're maybe going in where we don't need to.

Bill Gasiamis 49:26

So that's what we did. And I got to that point where everything was going well and I was great. And about two and a half years from the second bleed. I had the third bleed. And when I went to the hospital, it was Kate Drummond, my surgeon who said, we're going in this time.

Bill Gasiamis 49:48

I accepted I said no problem. She came back the next day and said I know I told you we're going in. But are you on board? Do you want to go in? I say I want this over and done with whatever comes, comes, it's time, let's get it done. And let's move on with life, regardless of what that looks like after the brain surgery.

Jenny Clarke 50:15

That was a vital element of your humanity, and helping you recover whatever happened to you, because you felt that you had some decision-making capability. Because when you're in a hospital, and you don't know what's happening to you,

it's very hard to feel as though you can do anything. And that's you or your family around you or your friends.

Jenny Clarke 50:47

And I think and lots of people say, to me, recovery starts in the acute state. And it's a great thing to say, but I don't quite know what it means in practice, because I think we're so again, use a word that will use a lot fragmented in our approach. And the pathway of care is so fragmented, and so haphazard because it's not systematic.

Jenny Clarke 51:16

It depends on which hospital you're in which level of hospital you're in, which country you're in which town you're in, and how long it's been since you've had your trauma to actually being recognized as needing treatment. So I think that that is such an issue.

Jenny Clarke 51:35

And I think that the recovery should be you understanding the bigger picture and being told the bigger picture quite early on. And again, that's not medical practice, people only will give you the information that they think you need to know, one day at a time.

Bill Gasiamis 51:55

And yet, they will give many stroke survivors, the bigger picture on the downsides, the possible downsides it's like, you probably never walk again, talk again, do anything and it's like, hang on a second, you know, how about giving me the what's possible speech? I don't get that at all. That's so strange, and yet, I hear about it still to this day in 2023. I hear about it almost all the time.

Jenny Clarke 52:24

Absolutely. And so I talked to a great group of neuro neurologists in the States, who, you know, when we launch said, you know, we'd love to see how we can support you because our membership in the States, 1000s, of neurosurgeons and radiologists, you know, that they don't have the understanding that you can recover.

Jenny Clarke 52:49

Because today people are told, okay, that's it, you had a stroke. You know, we can't do any more for you. You are where you are, which is patently untrue. Yeah,

so that it's, you know, it's not to I don't think it's too high blown to say, we need a revolution in thinking to, you know, to every sort of, at every level, you know, we need wonderful neurosurgeons and doctors to understand the implications of their words, on patients and their families.

Jenny Clarke 53:28

And while they are doing it, for whatever reasons they're doing it, there has to be an understanding. People have to have hope. Because if you haven't got hope, where can you go? Yeah, and there's always hope, you know, any, there's no one I've ever met or talked to, in this journey of the charity, that, you know, that can't have hope.

Bill Gasiamis 53:54

So, it's been a pretty heavy episode so far. But I want to transition from that because I did interview an amazing guy, Dr. J Mocco MD, MS for World Stroke Day 2022. And he's a vice chairman of neurosurgery in the particular hospital that he works in in the United States. He's part of an organization called Get Ahead of Stroke. And we had an amazing interview and he was so upbeat and encouraging.

Bill Gasiamis 54:32

And I clipped certain sections of the podcast interview specifically because and I quote, I'm going to quote him and I'm going to read a little bit transcript and this is what he said. I want to make sure that people know there is hope, and we are making some kind of headway he said.

Bill Gasiamis 54:52

"What I want to highlight is a positive thing that you just said and that I think is worth broadcasting which is people would say that after two years, they tied their shoelaces after three years, they walked a few miles. So that's important with stroke, one of the amazing things is that you can keep getting better even after two years. And three years later."

The Importance of Mental And Emotional Support

Jenny Clarke 55:16

Yeah, right. And, you know, it is, there is the equation of physical repetitions of

exercise to be able to tie your shoelace, or to walk or to lift a cup. We also think that there is a parallel to that such a big part of life is the mental and emotional support that you need.

Jenny Clarke 55:46

Because while you're doing physical repetitions? How would you get the motivation, day after day where you don't see the changes that you pray and hope for immediately? Because it's a slower recovery how do you keep motivated, and keep your mind alert that will in turn give you a lot more in your life when you think it's all darkness.

Jenny Clarke 56:15

So I think having, you know, a structured approach to emotional recovery is vital. And I started Emilia and I started talking about emotional recovery right at the beginning. And you talked to neuropsychologists and clinical psychologists, and that's one of the words they use to describe, but language is so clumsy, isn't it? I think the whole words that are around all of this issue, you know, people understand to a certain degree that a stroke is a brain injury.

Jenny Clarke 56:45

What does that mean? So many types of brain injury. And somehow, you know, we say all the time in the charity, obviously, and we hear it all the time. And it's just, it's a confusing name. And then when you think about emotions, and emotional recovery, you know, depending on who you are, as an individual, you could think, well, how important is that?

Jenny Clarke 57:10

Is that just that very girly? Is it you know, you're using all sorts of discrimination language to you know, to pigeonhole you? Anyway. So I just think when we talk about mental health and recovery, it's more helpful. Because there is at least a level of understanding about mental health as well as physical health these days.

Bill Gasiamis 57:35

I love that. I love what you just said because at least the conversation about mental health is starting to happen and people are aware of it. So it's one way to infiltrate the hearts and minds of the people that we need to get on board.

Bill Gasiamis 57:51

Because you're right, going to the emotional part of the recovery does, you know,

mess with people, I know that because I am advocating for emotional recovery, after stroke as a very important second step to the physical recovery that happens after the hospital. And when you put it out there, when you put out there the words, the emotional recovery, people don't grasp the concept.

Bill Gasiamis 58:24

And often they've got their barriers around going to emotionally challenging spaces in their own heart from past traumas, past relationship issues, or past challenges around emotions. And therefore, you're thinking about, you're looking at the peak of the mountain, you're thinking of, I've got to be right at the peak of the mountain now and not realizing the path that's ahead of you.

Bill Gasiamis 58:53

And that becomes overwhelming. And it's like, we're not going there. But at least the conversation about mental health has started to come into our vocabulary. And people are getting appreciation for what that means, especially after two years of lockdowns, COVID restrictions, and all the stuff that we went through. Because most people can relate to that now.

Bill Gasiamis 59:16

But I like to tell people that stroke recovery is a mental, physical, and emotional approach. It's a three-pronged approach, and you have to address every one of them equally. Because if you don't do any emotional recovery, after a stroke, and you just do the physical recovery, you're creating emotional energy around your stroke and your recovery that gets in the way of the rest of the physical recovery that needs to happen in the head.

Bill Gasiamis 59:57

And the mental recovery if that's not dealt with then you also get in the way of the physical recovery that has to happen in the head. And then you're not supporting the body efficiently and well, because you're wasting energy, overthinking things and becoming distressed and becoming anxious and becoming depressed and a whole bunch of other things.

Bill Gasiamis 1:00:26

So I feel like part of the journey for me that made me brag about my success and brag in a lovely way to encourage other people to brag about my success was that I feel like I'm fully healed. Even though I live with deficits every single day, I feel

like I'm fully healed from my stroke experience, because I was able to do all the mental health work, the emotional health work, and then all the physical work that put me back on my feet, and made me my ball and access and be a part of my community.

Jenny Clarke 1:01:17

Yeah, you're so right. So it's an artificial barrier between your mental health and your physical health. It shouldn't exist. It's a project of 21st or 20th-century medicine. And hopefully, in the 21st century, that is going to change. Because it is about, you know, we have a wonderful supporter, somebody who had a very serious brain injury. And she's a copywriter.

Jenny Clarke 1:01:44

And she's worked with a wonderful animator who's got a fabulous, we have a wonderful animation, which is the words of people recovering from brain injury, explaining what it's like, to people who don't know, and that's on our website, and I can send you a link.

Jenny Clarke 1:01:57

But this wonderful girl said, that brain injury just doesn't happen to the brain, it happens to the whole person. And that is something that has to be acknowledged because of the complexities of this. To me, that's one of the simplest ways of defining what a brain injury is.

Jenny Clarke 1:02:15

It's a trauma that happens throughout your body your mind and your brain. And there are no, there's no difference between your brain and your body. It's gotten in terms of healing and recovery. It's got to be done simultaneously and have as much effort put into it.

Bill Gasiamis 1:02:34

Completely agree with you. When I went to my psychologist recently and had a conversation about overcoming life's challenges, we got to the part of the conversation where I challenged her understanding of the origins of the word psychology. And because I'm from a Greek background, I think I've got a bit of an advantage.

Bill Gasiamis 1:02:58

And she was kind of a little bit perplexed that I would ask that question, and she

wasn't able to give me an answer. And that didn't diminish her ability to support me and be an amazing guide in my life. Not. But it gave me an insight into the world of help. If somebody is a psychologist, and they don't know, the origin of the word psychology, and what it means that shows how far away we've come from, and where the healing needs to be.

Bill Gasiamis 1:03:42

And the fact that we've elevated the head to the point of being the most important thing that we need to pay attention to, and provide resources to. And we're missing the other part. So I had, of course, researched the word I had read about it extensively over the years, and I knew about it, because I have a Greek background, and I'm pretty fluent in Greek.

Bill Gasiamis 1:04:02

And then I Googled it, like I have just now so I can read it to you. And the origin of the word psychology is formed by combining the Greek word psyche, which means soul. And, then with the word, logia, which is words, but also reason.

Bill Gasiamis 1:04:31

So it's and logos refers to the head, it does kind of refer to the head. So it's kind of a combination of these two words. And what I get from it is that it's about the it's like the soul logic. Its first word in the word psychology refers to the soul the psyche and then it refers to logic.

Bill Gasiamis 1:05:02

And when you have a conversation with somebody who's a psychologist and has been to school for probably 10 years and is amazing at their job, but they don't know that, it just shows where the disconnect is from the professions that help, and why sometimes they miss the mark and aren't as effective as they could be in guiding people to get beyond the mental health issues and the emotional issues and all the stuff that they go through.

Jenny Clarke 1:05:39

So what are we going to do about it?

Bill Gasiamis 1:05:40

What we're going to do about it is we're going to continue this journey, and we're going to support each other. And we're going to promote organizations like Same You, we're going to continue bringing together people who are on our team who

think the way that we think and who have the backgrounds that we need them to have.

Bill Gasiamis 1:05:40

Like Dr. J Macco, for example, and all the other people that I've interviewed who are advocating for change, we will make a difference. It's just a matter of how big you want to make this how much time you have in front of you, and how much effort we're all willing to make.

Jenny Clarke 1:06:31

Well, everything, I think that the whole way forward is based around giving people their permission to do something about it. We've talked about this a lot. So building communities that will make a difference. I don't know how to do it. I wish I knew how to do it. But I know that what needs to happen is there needs to be a call for change from the people who have been affected by the change.

Jenny Clarke 1:07:03

So you've got these huge issues like climate change, and we're all affected by that. But it's the vanguard of people who see what's in front of them that make a difference. But with something like cancer when I was a child, which is a long, long time ago, and my mother's large female family all had cancer of some sort.

Jenny Clarke 1:07:28

It was a secret, it was a stigma. It was ashamed, you had to be ashamed. And you didn't mention the C word. And we were whispering about it. And so the secrecy around that, which has completely changed by so much effort by so many people, that I sort of equate, that's where we are with brain injury and stroke problems because people are people still see having a brain injury as having something to be ashamed of.

Jenny Clarke 1:08:03

And something that is a stigma associated with it. It took Emilia a long time to talk about it. And we were told that she shouldn't talk about it. Because nobody wants to hear about people with a brain injury. Because it means that something's wrong with you.

Jenny Clarke 1:08:21

And if you look around the world, how many people with a public profile stand up and say, I've had a stroke or a brain injury? You can name about four or five

people. And sometimes they are way, way older than when it's happened to them.

Jenny Clarke 1:08:40

So I think that there's a reason for that. And we've got to have everybody banding together to saying, well, you know, what's the stigma, if something happens to you? It's not anything that you can do something about, but you can take control of the way people view you and view your identity.

Jenny Clarke 1:09:00

That's, I think, vital. We need to start a movement for change. And we've got we've got everybody who's experienced it. They're the people and we've got to find mechanisms to help people come together to build communities in their local area, to connect to other communities.

Jenny Clarke 1:09:19

And then it's got to have a life of its own, because they use a lead movement for change, demanding better recovery services, demanding a better understanding of the issue, and demanding a change of attitude for people who are trying to live their lives after something's happened to them.

Jenny Clarke 1:09:39

Just like cancer, you don't look at somebody with cancer and judge them. But there's judgment with people. When you think you're meeting somebody with a brain injury, and you've alluded to it, you know, I've met so many people, you know, they can't handle that change at a supermarket checkout, and people sort of push past them and think they're drunk, or on drugs, or, you know, there's a lot, you know, just a lot.

Sharing Your Stroke Recovery Story

Jenny Clarke 1:10:06

So we need to start somewhere. And so what we've been trying to do is just by starting to say to people tell your story to us, because Emilia launched the charity on the 21st of March 2019. And she said I've told you my story because she told it to the New Yorker to the edge of the New Yorker. And she explained what happened.

Jenny Clarke 1:10:30

And she said, Now you tell me your story. And so our charity is being shaped by the response. Because when we started the charity, we didn't know what to expect. We were sure that we wanted to find funding to help with research, particularly for young adults after brain injury. And we also see that there's a lack of training in mental health.

Jenny Clarke 1:10:56

And we see that there is a lack of innovation. When we're mainstream technology, like, you know, using Zoom that we're doing now, can be used with clinicians to do group therapies and recovery programs. And the COVID, we were able to do that in the UK with COVID. And we funded a pilot that has gone on to get extra funding from other people. And so now with that spreading in the UK.

Jenny Clarke 1:11:24

So there are so many things that we can do, but the thing that is extraordinary about our charity is that shaped by people who have experienced brain injury in their families because we have something called portraits. And I have a team of three amazing volunteers. And Viro, who you met, is now working for us doing other things as well.

Jenny Clarke 1:11:45

But she has been managing a team. So people write to us, and we ask them if they want to tell their story in public. And generally, people do. Because sometimes people say it's the first time they've ever really talked about it and being honest. And that is a therapy in itself.

Bill Gasiamis 1:12:06

That's my experience with stroke survivors who come on, haven't spoken to anyone about it for 10 years, and decide that the first person they're going to speak to about their stroke is me on the podcast that goes out to the whole planet.

Jenny Clarke 1:12:22

We've got to learn from that. I mean, everything is a learning experience, isn't it? Because these things are just so many, there are still lots of secrets in here when we have to just get rid of all secrets to deal with brain injury.

Bill Gasiamis 1:12:36

Yeah, who are some of the partners that you guys have come together with?

Jenny Clarke 1:12:42

So in the States, we started with Spaulding rehab, Hospital Boston. And so we funded through Emilia, her own money, and also doing silly things online when she was in Game of Thrones that people wanted to donate to win, opportunities to meet her and be on the red carpet.

Jenny Clarke 1:13:04

So we raised a lot of money by the generosity of all of her fans. And so we've funded a major three-year program, where the particularly young investigators and Spaulding a wonderful hospital, part of the Harvard Medical Group, are looking at why some people are resilient, more resilient, in their approach to recovery than others.

Jenny Clarke 1:13:27

So that's something that hasn't been looked at too much. So that's happening. And that's a very big project. We then worked with the Royal College of Nursing in the UK, and said, we want to see how we can support nurses because that's something we haven't talked about. But we see how important nurses are to world health and individual health.

Jenny Clarke 1:13:50

So our journey was helped tremendously by Emilia as nurse Tina, that years and years after her first brain injury, we still were able to talk to Tina when there was a fear that something was going wrong. So we funded the first-of-its-kind training program for neurological nurses to look at how important research is that's one module, how important mental health recovery is never been looked at before, and then obviously, the physical recovery.

Jenny Clarke 1:14:21

So it's a program that's run by Edinburgh, we're in the second year. And we would love to be able to put that to different hospitals and universities and to share the learnings because it's something that's just very little training. So that's the Royal College of Nursing at Edinburgh University. We're also funding starting a major research project with Edinburgh again through the World College of Nursing to see if we can identify the need in terms of sizable chunks of data about the need for neuro recovery, particularly in young adults.

Jenny Clarke 1:15:01

And so those are ongoing, major, major projects that we fund. And then we started working with UCL UCLH, Queen Square when we started the charity, the first office had, we don't have an office now because of COVID. And you know, who needs an office these days, but it was in Queen's Square, so we could be physically close.

Jenny Clarke 1:15:22

And so I've been working almost daily with UCL experts in rehab. And so we started to do what they call neuro rehabilitation online enrollment. And I alluded to that earlier, which was just in COVID, when people couldn't come into rehab in a hospital, or community nurses can't go to it, or therapists can't go to you. How can you do it? So this is a program that can easily be taken by any hospital or any group of therapists around the world.

Jenny Clarke 1:15:56

There's a wonderful man, Professor Nick Ward at UCL, and he and his team and I worked on what that could look like. And so we have 10 people, 12 people on a screen with several people as a programmatic approach. So you can have, for instance, physiotherapy, you would think how could you do group physiotherapy, and that was the barrier. At first, the clinicians themselves didn't think that it was going to be effective and impactful.

Jenny Clarke 1:16:24

But they worked out very quickly, if you had two physiotherapists one giving the exercises, and the other one watching and noting down what people were doing and able to do course correction. That worked. They also included something wonderful called Carers Cafe as part of this digital group therapy, to talk to the husbands, wives, partners, lovers, children, you know, parents, to get them to talk about the issues that they face.

Jenny Clarke 1:16:56

So that's been great. So we funded that for six months in the UK in London. After the funding ended, and we couldn't afford to do it anymore, they got together themselves as a peer-to-peer group, and then we got some more funding from the wonderful UK National Lottery. And so that's not being rolled out in Lancashire, with another hospital group, where they've taken their therapists and what they look like because every group is different.

The Biggest Project by Jenny Clarke And Same You



For brain injury
recovery

Jenny Clarke 1:17:20

And they've interpreted the Enroll concept to fit what they can do as an addition to their recovery programs. And we're on the verge of the National Health Service, seeing if they can be commissioned, so it's going to be rolled out. And maybe it is, maybe it isn't. But that's one of the things we're doing. And then our big project is a real blue sky blueprint for what could a recovery center of the future look like.

Jenny Clarke 1:17:51

So I've been working with UCL for years on this. And we built it and built it and built it. And so it's massive, and it's far too big to try and get funding for. But we're just on the point of getting some funding fingers crossed in the next couple of weeks, where we can start to work in a small way to work out the feasibility of a mental health pathway. And the idea of a feasibility study is to interrogate researchers as well as clinicians.

Jenny Clarke 1:18:21

And so it's going to be acceptable as an evidence-based, cooperative program, where patients and their families are saying what they need and want for mental health support. And so we hope we've got the funding secured for that. And that's going to be a six-month program. And then we hope we'll get funding to pilot that in London, and then build that into something that we can now see as a vision of prevention and recovery center that can be lifted and shifted around the world.

Bill Gasiamis 1:18:54

Wow. Sounds like you've been busy.

Jenny Clarke 1:18:57

And we haven't got the money. So anybody listening to this would like to get involved. Please send me an email at jenny12@sameyou.org

Bill Gasiamis 1:19:09

We're gonna have all your details there so people can connect with you. I love the sound of the possibility of a specialized hospital or specialized care facility for people so that you guys can take them through the whole holistic approach to recovery from a brain injury.

Jenny Clarke 1:19:31

Using the performing arts, using the visual arts, using the environment using healing buildings using different things.

Bill Gasiamis 1:19:40

You may be aware that Olivia Newton-John was a resident of Melbourne before she hit the big time and became popular in the United States and around the world. As a well-loved Melburnian. She was very heavily involved because of her couple of cancer diagnoses earlier on in her life.

Bill Gasiamis 1:20:09

She was very big and she played a massive role in creating a similar type of center in Melbourne called the Living Olivia Newton-John Center, I think that ONJ Cancer Center they were able to bring in things like music therapy, and a whole bunch of other things. And my wife who's doing a psychology, psychology degree by the way, knows the origin of the word psychology. She's doing the final years of her master's.

Bill Gasiamis 1:20:58

She was able to as one of her projects, she was able to do a study to see how people responded to what I'm pretty sure was music therapy. And reported back to you know, school the findings, it was an amazing insight into how, with enough noise, for lack of a better word.

Bill Gasiamis 1:21:29

You're able to create and generate the movement that brings the people together, that raises the money that funds the center that allows people who are experiencing cancer to go to and have the medical treatment and in the same place have all the other necessary treatments that support the medical system, and add quality of life.

Bill Gasiamis 1:22:04

While people are going through some of the hardest times of their lives, so it's not like it has never been done. And I feel like you're on the verge of something

amazing. You know what they say, to be an overnight success, it takes about five to 10 years, so you're not that far off.

Bill Gasiamis 1:22:24

And then one day you'll be an overnight success, I'm very happy to get behind the work that you guys do. It's exactly why I started the podcast to raise awareness about not only what it's like to be a stroke survivor, or a caregiver for a stroke survivor or a family member or a stroke survivor, but also to bring awareness to amazing organizations like Same You that are doing the type of work that I would have benefited from if it existed where I live.

Bill Gasiamis 1:22:54

And it's so challenging for me to thank people for doing the work that they're doing. The only reason I know you're doing the work that you're doing is because you've gone through something traumatic and life-threatening and difficult. And you're living with, you know, some things that are in your head that you've got to contend with.

Bill Gasiamis 1:23:21

So I'm really glad that we connected I don't feel that this is going to be the last time we connect and work together or support each other. I feel that I'm on board. I'll help wherever I can. And however I can. And if anyone wanted to donate to sameyou.org, how would they go about it? What's the best way?

Jenny Clarke 1:23:48

Well, it's very simple. It's on our website, sameyou.org You'll see buttons everywhere saying donate. And you go into a simple system where you can donate in any currency. And you'll also see the things that we're doing. Not just the portraits, and the stories, we have recovery home videos the people have donated. We have a wonderful neuro directory, which at the moment is only in the UK.

Jenny Clarke 1:24:16

We've got working we're working with UCSF in the Bay Area in the States to try and extend that. We'd love to have, you know, Australian ideas and therapists and clinics and hospitals that might want to get involved. Everything is most of what we do is funded by volunteers and are funded in terms of we have 21 volunteers around the world, some in Australia, and certainly some in New Zealand with a wonderful Veronique.

Jenny Clarke 1:24:46

And across the states where people are giving their time to help Same You you because we can't afford, you know, great graphics and you know, we have to pay, you know, hundreds of 1000 for its agencies. So we get through making graphics for people who are wonderful at it. And they just donate it and do their time. So we have a fantastic group of people that support us now.

Jenny Clarke 1:25:08

But so you can donate, you can see the things, the campaigns that we run, you can see our new buddy program is going to be online soon where we're starting in the UK. So we have buddy people helping each other. Because they've gone through it just as you're trying to do with you and are doing with your podcast, how your experience is helping others with a program and on neuro directory.

Jenny Clarke 1:25:31

And, I think that by coming together and extending that, and extending a community and seeing how we can start to talk to build a movement. That would be phenomenal. If anybody was listening to this, that's got experience, ideas, and energy around it. Maybe they talk to both of us.

Bill Gasiamis 1:25:54

Yeah, absolutely. I look forward to it. Anything that comes my way, I will pass your way. But at the same time, anyone that's listening. At the end of the podcast, we're going to have the show notes, there'll be the show notes recoveryafterstroke.com/episodes. That's where you'll be able to get all the contact information for Same You.

Bill Gasiamis 1:26:17

You can sound like you can donate your time as well as money if money is not something that you can manage to donate. And you can also donate your creativity skills if you've got skills in creating something for the team that they want to put out whether it's a flyer or graphics, or whatever it is. So that's amazing. You can do that. Jenny, thank you for being on the podcast. Thank you for reaching out.

Jenny Clarke 1:26:47

I've enjoyed it so much. And thank you for doing what you're doing. It's brilliant and will make a difference to so many people I know.

Bill Gasiamis 1:26:57

Thank you once again for joining us on today's episode. I just love the work Jenny and Emilia are doing and the organization that they have set up, I'm thrilled that they are doing the kind of work that is making a massive difference to people's lives. Now 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 1:27:23

There you'll find links to the same you donate page and if that's something that you would like to do, they accept donations in any currency. And as well as that you'll find the link to the short film untold stories of brain injury voices from stroke survivors. Go ahead and check it out. If you'd like to support this podcast, the best way to do that is to leave a five-star review and a few words about what the show means to you on iTunes and Spotify.

Bill Gasiamis 1:27:51

If you're watching on YouTube comment below the video it's really important and it makes the video accessible to a whole bunch of other people like this episode and 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 join me on the show.

Bill Gasiamis 1:28:14

Interviews are not scripted, you do not have to plan for them all you need to do to qualify as a stroke survivor is care for someone who is a stroke survivor. Or you're one of the fabulous people who help people who are stroke survivors just like Jeyie and Emilia.

Bill Gasiamis 1:28:31

So go to recoveryafterstroke.com/contact and fill out the form. 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 truly appreciate you see you on the next episode.

Intro 1:28:51

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treatment 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 in all content on this website at any linked blog, podcast, or video material control.

Intro 1:29:13

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Intro 1:29:36

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Intro 1:29:52

If you have any questions or concerns about your health or medical condition, please seek guidance from a doctor or other medical professional if you are experiencing a health emergency or think you might be, call 000 if in Australia or your local emergency number immediately for emergency assistance or go to the nearest hospital emergency department medical information changes constantly.

Intro 1:30:12

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