# *enable****me*** Podcast episode 4 transcript

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| Announcer: | Welcome to the *enable****me*** Podcast Series, where we bring together stroke survivors, health professionals and researchers providing you with practical advice to enable you on your journey to reclaim your life after stroke. |
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|  | You can join the conversation at [enableme.org.au](http://enableme.org.au/). |
|  | The series is presented by Australia’s national Stroke Foundation and sponsored by Allergan. |
| Chris: | For many people who’ve had a stroke, fatigue is one of the biggest disabilities that they face. It's more than just regular tiredness that can be relieved by a good night's sleep. Fatigue can hold back your recovery and can keep you from getting your life back to normal. It's also an invisible disability, meaning that it can be hard to get support. |
|  | But there are things that can be done. To find out more in the studio today we have Dr Toby Cumming from the Florey Institute Of Neuroscience And Mental Health. He's currently running a study called the Fatigue After Stroke Trial, or F.A.S.T.—not to be confused with the other stroke FAST. Welcome Toby. |
| Toby: | Thanks a lot. |
| Chris:  [00:01:00] | We also have one of their regulars, occupational therapist Simone Russell from the Stroke Foundation’s StrokeLine, who frequently has people calling her to talk about fatigue. Hello again, Simone. |
| Simone: | Hi. |
| Chris: | On the line we have Brenda Booth, a registered nurse and disability caseworker who had a stroke when she was 41 years old. She's now a member of the Stroke Foundation’s Consumer Council and making sure that consumers have a voice in the provision of stroke services. Thanks for joining us, Brenda. |
| Brenda: | Thank you for asking me. |
| Chris: | All right, now I’ll start with you Toby. As someone who's conducting research in this area, how common is fatigue after stroke? |
| Toby: | Very common. We think it's about 50% of stroke survivors experience fatigue. I've actually just completed a review of the literature that identified about 50 research studies that looked at post-stroke fatigue and we could pull out about 22 of those studies that used the same assessment tool. So that made comparing the results between those studies pretty easy. |
| [00:02:00] | The end result was 50% basically, about half of stroke survivors with fatigue. One of the interesting things that came out of it was it's also quite variable across studies. Some studies seem to show only about a quarter of stroke survivors with fatigue. Some studies suggested three quarters and we really don't understand that variability in how common fatigue is yet. So that's what we're looking at next. |
| Chris: | When we're talking about fatigue, we mean physical, mental and emotional, is that correct? |
| Toby: | Absolutely yes. Some people I think when they think of fatigue, they think of physical, but mental fatigue is also a big issue for a lot of stroke survivors I think. And it's important to note as you said at the start that it's not just following periods of activity. It’s not just feeling tired after a 30 minute walk or reading the paper for an hour. It’s not necessarily brought on by any physical or mental activity. It can happen at any point. |
| Chris: | Simone, does that sound like what you’ve heard? |
| Simone:  [00:03:00] | Yes. Look absolutely. I think similar to what Toby has mentioned about the variability, I'd say most callers would say they’re experiencing some level of fatigue. The degree also is quite variable. Some survivors might call in and say that they've been unable to return to work due to their fatigue, whereas someone who may have recovered quite well from their stroke may say they just noticed they're a little bit more tired than before. |
|  | But yeah, absolutely there is definitely fluctuations in the level of fatigue reported and also some survivors who don't have fatigue at all definitely call in as well. But it's definitely a common theme after stroke. |
| Chris: | Okay now, Brenda, I know that you have experienced challenges with fatigue yourself. I'm wondering, could you start by telling us your stroke story? |
| Brenda: | As you said, I was 41 and that was back in 2001, so 15 years ago. It was completely unexpected. I had no risk factors, you know, my blood pressure was good, everything was good. My stroke was completely out of the blue. I lost my ability to speak, half my vision, I lost the movement in my arm.  But fortunately I was really lucky. My stroke symptoms were recognised really quickly and an ambulance was called. What happened when I got to the emergency department was my arm and my vision returned to normal. |
| [00:04:00] | My speech didn’t. My word finding was really quite affected.  Then after I was in the hospital, I started very, in quick order, having multiple TIAs, so mini strokes. And they found that what had happened was I had a tear in my internal carotid artery, which is called a dissection, and I'd had a middle cerebral artery stroke.  I don't have a physical disability. I'm very lucky and people will often assume I’m fully recovered, which is really … it's good that I’m as able-bodied as I am, but I struggle with the hidden disabilities of stroke and I also struggle with the fact that people assume I’m back to normal. |
| [00:05:00] | The disabilities that I have my memory, my concentration is really affected, my speech particularly when I'm tired, when I’m fatigued. People who know me well can tell. That's my story in a nutshell. |
| Chris: | With the fatigue then, as you said it is hard for people to know what you're going through. What does it feel like? What's the experience like? |
| Brenda: | It's what Toby and Simone both said, not only just the physical fatigue, it's the mental fatigue. Many many years ago, I had Dengue fever, so I know what it's like to have extreme physical fatigue. But I've got to tell you the post-stroke fatigue that I’ve experienced, it's mind-numbingly impactful. It's like I hit a brick wall and I just have to stop. As I said, when I’m fatigued, my speech is so much worse. My word finding is worse. |
| [00:06:00] | Not that long ago, I had got back to work, but I had an agency that I was working with. Now I couldn't get my words out and they said, “Oh, you must have had too much to drink at lunch today.” The other thing that is affected when I’m fatigued is my memory. I just go blank. It's more manageable now than what it was when I first had my stroke 15 years ago, but that said, it still really does affect me. |
| Chris: | Simone, I’m interested to know from your experience as well, do you find people also not knowing what the person with fatigue is going through, like family and friends not understanding? |
| Simone: | Yeah absolutely. I think as Brenda has mentioned, it really is one of those silent, I guess, ongoing impairments that you can experience after stroke and that can bring about its own frustrations and I guess sense of isolation for the stroke survivor itself. But I know certainly some stroke survivors feel comfortable starting to educate family and friends, which can be helpful. And that might be through using some of our resources, fact sheets, directing them to *enable****me*** or to our website to read a little bit more about fatigue, to really say, well actually it is something that exists. |
| [00:07:00] | Also some stroke survivors use different terminology when talking about their fatigue. I know certainly conversations on *enable****me***, stroke survivors, they’re using the term, say “brain fog” or “rubber brain”, to really use terminology that their friends and family might get. Sometimes also suggesting to family and friends, I've got a time limit. I think Brenda said, where you hit the wall, that can be really helpful to use those sorts of terminology with family and friends, to get them to really understand that it is a really big issue for them after stroke. |
|  | Talking to health professionals as well can be really beneficial to really get that understanding that this is a really big concern for a lot of stroke survivors and it can totally impact on their life after stroke. |
| Chris: | Toby, I get the impression that part of the problem here with people not understanding is just that there’s the mystery around what causes post-stroke fatigue, and that it is something that people experience. Do we know what brings it about? |
| Toby:  [00:08:00] | The short answer is no, we don't. The review I spoke of before where we pulled 22 studies out that looked at one specific outcome measure, that actually had 49 studies in it, that entire review, and all but two of those were published since 2005. If you think of the research literature on post-stroke fatigue, it's 95% in the last ten years which is … it's the tip of the iceberg. We still know very little. |
| Chris: | So it's very new in terms of the actual science and the research? |
| Toby: | It is a very new topic, which I don't know why it took so long to pick up on given how marked a problem it is for survivors and it gets reported a lot. And a lot of the research to date has been showing that things are associated with fatigue. We know that physical disability levels are associated. We know that depressive symptoms are associated with greater fatigue, but really that can be a two-way street. So in terms of identifying causal factors, we're still a long way off. |
| Brenda:  [00:09:00] | Look, one of the things that, my thought to that Toby, is things that used to be automatic for a person prior to their stroke, now require so much more concentration. And if you’re doing that for all the activities that you used to on a daily basis, now you’re really having to think about it. I’m just wondering whether that would be part way to a causative factor. |
| Toby: | I think that’s a great point, Brenda. In fact one of the things I'm really interested in is not only what causes it, because I think the way I think about stroke is this major medical event that stresses the body. It stresses the brain and there’s huge downstream effects. I'm not surprised that people get fatigued in the first few weeks and it's probably even a good, restorative, adaptive response. |
| [00:10:00] | If you think about it in evolutionary terms, it's a horrible stressful event and the body naturally says to itself, I think you need to withdraw. You need to look after yourself. You need to try and recover in the short term. Like you say, there's cognitive inefficiencies, slower processing. There's physical inefficiencies. You’re often weak and trying to get back to walking. There's a massive range of effects that can happen after a stroke. |
|  | What I’m interested in is not just what causes it in that first early phase, but why… As you say, lots of your other symptoms resolved and yet fatigue was still a problem, particularly this cognitive mental fatigue. What is it that makes the fatigue go for years even when those other things have resolved or at least improved? It’s not just what causes it but what keeps it going is what I’m interested in. |
| Chris: | Brenda, you said that you had had some improvement in the years since your stroke? |
| Brenda: | I did. I did have improvement. I found that the frequency, not the degree, but the frequency was better. However, a couple of years ago I became critically ill and I was in hospital for a couple of months and in and out of ICU. I found that my stroke fatigue—and during that time actually I didn’t have another stroke, but I had a number of really serious episodes of low blood pressure that put me in ICU. |
| [00:11:00] | I found that my post stroke fatigue completely refreshed and it was almost back to where it was when I first had my stroke. I’m actually still dealing with the fatigue from there. I’m back at work, but I tell you, the fatigue is still knocking me around. |
| Announcer: | *enable****me*** is Australia’s online stroke community. |
|  | It’s a place where stroke survivors, their carers and supporters can find information, share their experiences and inspire each other with their recovery. |
|  | Signing up is free and takes just a minute. It allows you to post questions and comments, set and track your own recovery goals and connect with people who understand exactly what you’re going through. |
|  | It’s filled with evidence-based resources, videos and stories. It’s everything you need to grow stronger after stroke. |
|  | Sign up now in seconds at [enableme.org.au](http://enableme.org.au/). |
| Chris:  [00:12:00] | Simone, something that I’ve seen mentioned in some discussions on *enable****me*** is people talk about pushing through fatigue and it seems to be that some people say they’re able to push through like that. Do you think that that’s a real thing? |
| Simone: | Yeah. Look, I think everyone’s different and I think that the fatigue is unique to that person. I think some people will push through because they don’t necessarily have a good awareness of their, perhaps new limitations after their stroke. They may take some time and education to get to know their body post-stroke. But you will also have people that have post-stroke fatigue that have to push through, otherwise they would be stuck potentially on the couch or in bed most of the day and unable to do much else. |
|  | I’m curious though to find out too if Toby has any thoughts on this as well. It is a really big discussion in the stroke community, to push through or not, to rest more, to rest less. Obviously we know exercise is really essential even with fatigue, but it is that fine balance and trying to work that out. |
| Chris: | This is probably a good time to ask Toby about some of the interventions that are used for fatigue. Now, I understand as I mentioned in the introduction, you’re doing a trial, it’s a fatigue after stroke trial. Can you tell us what kind of treatments that you are looking at in that trial? |
| Toby:  [00:13:00] | Yeah, sure. Physical activity basically and this is exactly the question that we’re trying to resolve. When is rest good? When is more activity good? We don’t know at the moment. I think if one thing comes out of this study, if we can answer that question, then that would be a massive success. Because at the moment, I think clinicians don’t really know what to advise. |
|  | The general feeling is that maybe when you’re feeling fatigued that you should rest, but equally, we know a lot of the things that contribute to fatigue are muscle deconditioning, lack of fitness, poor sleep, depressive symptoms. All these things can be positively addressed by increasing physical activity. This is essentially what my study is aimed at teasing out. When should you be more active, even when you don’t necessarily feel like getting up off the couch, and when have you had enough and you need to rest, and if you keep being more active then it’ll just wipe you out for tomorrow and the next day. |
| Chris:  [00:14:00] | Are there other treatments that have helped counter fatigue as well? There’s been a bit of talk about different medications and drugs that might help. Is there anything in the horizon with that? |
| Toby: | The big picture story is the Cochrane review that came out last year which is the gold standard, pulling all the treatments together for post-stroke fatigue. This was a study reported from the Edinburgh Group, Gillian Meade and her colleagues. They identified 12 studies of the highest quality, randomised controlled trials that have been done to try and address post stroke fatigue. Sadly, their conclusion was that there’s insufficient evidence to support the use of any intervention to treat or prevent fatigue at the moment in people with stroke. |
| [00:15:00] | That’s what the gold standard Cochrane evidence says. It’s not quite as bad as that. There’s small trials. There’s other suggestive findings that hint that there may be some things we can do. Certainly drugs, modafinil is one of the ones that had some success in multiple sclerosis (MS) and fatigue resulting from MS. It has been trialled in one small stroke study, but it was 23 stroke survivors in that study, so still very small. |
|  | Our colleagues up in Newcastle have just run a study in looking at whether modafinil works for post-stroke fatigue. Again, fairly small. I think they recruited, they just finished recruiting 35 participants, but that’s certainly being looked at, yeah. |
| Chris: | Okay. Obviously we don’t have the results from that study yet. We’re waiting to … |
| Toby: | No, it should be soon I think. |
| Chris: | Okay, we also had someone ... We put a call out for questions for today. We had some other things people were asking about. One of them was something like dexamphetamine, which I believe is used for things like ADHD and other conditions like that. |
| Toby: | It certainly hasn’t been looked at in terms of post-stroke fatigue, no. Another class of drugs that has been looked at is the SSRI group which is often used for depression. Given the link between depression and fatigue, people thought this might be a good opportunity to look at whether that works. The findings have been pretty disappointing. |
| [00:16:00] | There was a large trial I think in 2007 that looked at fluoxetine, one of the big SSRIs that didn’t seem ... Even though it had good anti-depressant effects, in that trial it didn’t seem to resolve the fatigue at all. |
| Chris: | Okay, now with this connection between depression and fatigue, it’s not necessarily ... They’re associated, but they’re not necessarily both … You can have both of those at the same time, do they? |
| Toby: | It’s a really good point to make that they’re not the same thing. Yes, they are highly associated. Often someone who is experiencing depression will have high levels of fatigue as well after stroke, but you can certainly have one without the other. I’ve certainly seen quite a few stroke survivors that have debilitating fatigue with no signs of depression at all. |
| Chris: | The cause and effect I imagine would be very hard to tease out there. |
| Toby: | Absolutely, yeah. |
| Chris: | Okay, is there anything else that’s come up? I think that there’s also ... You had one you wanted to ask a bit Simone. |
| Simone: | Yeah. We’ve had a video posted on *enable****me*** around blue light therapy. I know Epworth have done a study in relation to acquired brain injury and blue light therapy. I was curious to know a little bit more about the evidence or plans, if you know if there’s any more research coming that way in that area. |
| Toby:  [00:17:00] | I think that was a fascinating study. Kelly Sinclair did quite a lot of work in TBI, but they actually did recruit some stroke participants as well to see if it reduced their fatigue. The blue light therapy, for those that don’t know is this ... It’s just a box with light shining at you basically, short wavelength versus long wavelength. It does something to trigger the retina and gets through to your attentional system in your brain. |
|  | Her findings were pretty positive. It does look like it increases attention. It did look like it had small effects on fatigue. So very early days for blue light therapy I think, but in terms of an easily available cheap, no-side-effect therapy, I think it holds promise. |
| Simone: | Were there any contraindications for say seizures or anything like that do you recall? |
| Toby: | Not that I’ve heard of, no. |
| Chris: | Brenda is someone who’s obviously gone through this yourself. Do you have any other things that you’ve found to work and to help with fatigue? |
| Brenda:  [00:18:00] | Look, I think ... You were talking about pushing through those limits and pushing the barriers. I think for me it was around being aware of what my limits were. One of my own ways of dealing with fatigue and all sorts of other issues in the stroke, but I returned to work part-time not full-time. And pacing myself and also cutting myself some slack, and not thinking I could ... I used to be ... Do what I used to do. It’s knowing when to listen to others. |
|  | There are times when it is good to push through. Certainly there’s times when you’re driving it’s not good to push through. Good to pull over and have a nap if you feel fatigued. It’s about just pushing your limits safely. |
| Announcer: | Setting goals is crucial to stroke recovery. Goals can be as simple as walking to the letterbox to check the mail, or bigger goals like getting back to work. |
|  | *enable****me*** has a unique tool where you and your carer or family can plan what you want to achieve, track how you’re progressing and celebrate your successes. |
|  | You can also connect with other people who set goals similar to yours and challenge or inspire each other. |
| [00:19:00] | You can even set up a blog to write down how you are feeling and share your own story. |
|  | Don’t forget our professionals from stroke line can help with personalised and confidential advice to help you grow stronger after stroke. |
|  | Visit [enableme.org.au](http://enableme.org.au/). |
| Chris: | Simone, I guess in light of everything we’ve heard today, can you give us some of your tips that you would give people if they call up about fatigue after stroke. |
| Simone: | Yeah, sure. Look, I have a number of different tips. It’s always very individualised depending on how severe the fatigue is, what someone else’s abilities might be, when they call up and where they’re at in their journey as well. If they’re just going home from hospital, the tips that I give might be quite different to someone like Brenda who is a little way down the track.  But they can involve anything from obviously listening to your body, starting to get to know your new limitations or your new abilities. That can take some acceptance and time to just adjust to what you’re capable of doing and what’s realistic as well in a full day. |
| [00:20:00] | A lot around organisation and planning, so trying not to plan too many things in one day if you do know that fatigue is an issue for you. And that might be spreading out your medical appointments across the week, or having different social outings so that they’re not all in one day. Certainly resting before you notice that fatigue setting in can be one advantage for some people that works, rather than say pushing through and then having a whole week out because you’re so exhausted. I tend to call that a fatigue hangover. |
|  | There’s a number of other things I suggest. Making sure that there is not anything else that you can tweak. Checking that your sleep is good quality sleep, you’re getting good quality sleep. That you’re drinking enough water, that you’re eating a really nutrient dense diet. That there is no nutritional deficiencies there that could also help with fatigue levels. Exercise, as we’ve touched on already, you do want to exercise. It’s really important to be getting up and still moving your body from a prevention as well as to be managing the fatigue as well. |
| [00:21:00] | There is obviously also seeking help. There are cases where people need to actually say yes to that offer of having someone come and bring meals in for the week or for however long. Getting a cleaner in some cases, for example, might be actually a really worthwhile investment. That can be quite challenging for people that may have always done everything before the stroke.  Certainly, we have a lot of stroke survivors in our community that practice mindfulness and yoga that find that that can be really beneficial in terms of having that time out. It may not be just resting, but they’re dong mindfulness or meditating instead. |
|  | They’re some of the suggestions Chris, but usually I tailor it depending on the level of fatigue, how far along they are in their journey and what else might be factors. As Brenda I think has touched on as well, fatigue will exacerbate pain and weakness, it can cause deterioration in someone’s walking.  It really depends on the person, but very happy if they call StrokeLine to give a tailored approach and *enable****me*** has also got some fantastic conversations. There is a whole number of conversations and really, really practical tips from other stroke survivors. |
| Chris: | Okay and Toby, have you got anything else to add, some advice you give stroke survivors? |
| Toby:  [00:22:00] | I think Simone has covered lots of the really important stuff. One thing I might add is that it’s important to, as probably the first line of management, to try and identify potential reversible medical problems. There’s lots of things that can cause fatigue, like pain or muscle spasticity or mood disorder, and these are all things that are potentially modifiable. I’d definitely say to talk to your doctor in the first instance to try and look at that. Sleep apnea is another one that’s very clear, treatable and can feed into fatigue. |
|  | I’d suggest reviewing medications. Quite a few medications that stroke survivors can be on, can have sedative effects, particularly anti-depressant and anti-anxiety drugs. So it’s really important to review what you’re taking in terms of medications. |
| [00:23:00] | Then we get to the lifestyle factors. Avoid alcohol if you can because that has sedative effects too. Have a good sleep routine including during the day. I know a lot of stroke survivors with fatigue tend to need to rest in the afternoon. If you do need to do that, try and limit it to not more than 20 or 30 minutes because otherwise, it might interrupt your sleep-wake cycle and that has a whole knock on effects to circadian rhythm and fatigue. |
|  | With physical activity, try and be regular. Don’t do too much even on your good days and try and do something even on your bad days, would be what I’d suggest. Although as we said, the research is out on that, that’s just a common sense guideline at the moment with not much to back it up.  I’d also say with support, support from people around you, from family and friends and peers in the stroke community, is very important, but also maybe don’t get too much support. It’s the same with physical activity. You want to be living your life for yourself and not having everything done for you, otherwise you might just feed into that negative cycle. |
| Chris: | Brenda, any final thoughts or advice you’d give other stroke survivors? |
| Brenda:  [00:24:00] | Yeah look, I think raising … What Toby said, raising awareness with people around you is really important. For the family and friends, but also for me, it’s my work colleagues knowing when I’m fatigued and there is not a lot of people at work who would pick up when I’m fatigued, but there is a few that just, they know.  I think also factoring in that time out, giving yourself a bit of a break, even in a busy day is useful. You don’t have to lay down and sleep. Just taking it easy is really important. Recognising it for yourself, it’s probably the hardest thing. Dealing with a stroke is hard enough, but then dealing with fatigue on top of it is very difficult. I know some people are very affected by fatigue. |
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| Chris: | Thank you all. Now if you want to speak to a health professional like Simone about fatigue or about any other issue, you can call StrokeLine on 1-800-787-653 or 1-800-S-T-R-O-K-E. |
| Announcer:  [00:25:00] | At Allergan, we know every stroke is different and so is every recovery. After stroke, many people have muscle weakness and loss of movement, but you might also be experiencing tight muscles or stiffness in your arms, fingers or legs, it’s called spasticity. You might have muscle spasms or uncontrollable jerky movements in your arms or legs. Changes in your posture or unusual limb positions, and it can cause pain.  It can be treated though. Physiotherapy or occupational therapy can help you adapt and improve your movement. |
|  | There are other possibilities too, such as injections with botulinum toxin type A, electrical stimulation of the muscles, electromyograph or EMG biofeedback, and muscle-relaxing medication.  What is important is to start your rehabilitation as soon as possible after a stroke and to discuss your goals and progress with your rehabilitation team at every stage. Allergan is proud to bring you this *enable****me*** podcast. |
| Chris: | Thank you once again to our guests Dr Toby Cumming, Brenda Booth and Simone Russell. |
| Toby: | Thanks Chris. |
| Simone: | Thanks for having us. |
| Brenda: | Thank you. |
| [00:26:00]  Announcer: | That’s all for today’s *enable****me*** podcast. You can find out more on this topic and continue the conversation or listen to other podcasts in the series at our website [enableme.org.au](http://enableme.org.au/). |
|  | It’s free to sign up and you can talk with thousands of other stroke survivors, carers and supporters. We also have health professionals from StrokeLine who can answer your questions and give evidence-based advice. |
|  | The advice given here is general in nature and you should discuss your own personal needs and circumstances with your health professional. If you would like to suggest a topic or provide feedback, contact us via the website [enableme.org.au](http://enableme.org.au/). |
| [00:27:00] | The music in this podcast is “Signs” by stroke survivor Antonio Iannella and his band The Lion Tamers. It was recorded at Antonio’s studio, which you can find out more about at [www.studiofour99.org.au](http://www.studiofour99.org.au). That’s F-O-U-R-99.org.au |
|  | This *enable****me*** podcast series is produced by the national Stroke Foundation in Australia with the support of Allergan. |