Overcoming Locked In Syndrome – Duncan Campling

Duncan Campling has been in recovery from locked-in syndrome since 2018. The father of two is living in a nursing home and due to Covid has not been outside in 9 months

Socials: www.instagram.com/duncan.campling/

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Transcription:

Duncan 0:00
When the first ambulance came to pick me up. I had completely flatlined. So I had no pulse. Also, I was totally motionless and paralyzed. The Medical Technician thought I had died and called my time of death in front of me, I wanted to stay I'm alive, but nothing came out. Shortly afterward, I was worried about being buried alive.

Intro 0:31
This is The Recovery After Stroke Podcast, with Bill Gasiamis, helping you navigate recovery after stroke.

Introduction

Bill 0:44
Bill from recoveryafterstroke.com This is Episode 133. My guest today is Duncan Campling. Duncan experienced two brainstem strokes in March 2018, and when he regained consciousness, he was locked in fearing he would be buried alive.

Overcoming Locked In Syndrome

Bill 1:02
According to the website, rarediseases.info. Locked-in syndrome is a rare neurological disorder characterized by complete paralysis of the voluntary muscles except for those that control the eyes.

Bill 1:16
People with locked-in syndrome are conscious and can think and reason but are unable to speak or move. Vertical eye movement and blinking can be used to communicate. Locked-in syndrome may be caused by a brainstem stroke, a traumatic brain injury, tumors, diseases of the circulatory system like bleeding.

Duncan Campling is Living with Dysarthria

Bill 1:37
Diseases that destroy the myelin sheath surrounding nerve cells like multiple sclerosis, infection, or medication overdose. Duncan is also living with Dysarthria, which is a motor speech disorder in which the muscles that are used to produce speech are damaged, paralyzed or weakened.

Bill 1:56
The person with dysarthria cannot control their tongue or voicebox and Duncan will be speaking with me via an adapted iPad, which uses text to voice software to allow him to communicate. His answers were pre recorded to make the interview process much smoother.

Bill 2:13
Now, if you have ever wondered what else I can do to help you with your stroke recovery, you should know that you can now get recovery after stroke coaching right from the comfort of your own home.

Bill 2:23

I too am a three-time stroke survivor and I've built for you what I was missing when I was sent home from hospital in the hope that you don't have to do stroke recovery as tough as I did.

Bill 2:33
Support packages give you access to a variety of tools 24 hours a day seven days a week so that you can also work on other areas of stroke recovery, like adjusting to your new normal, and even managing the grief you may be feeling for your former self.

Bill 2:47
With tailored support available and designed for you. You can now try our recovery after stroke catching free for the first seven days and get a full refund if you aren't satisfied after 30 days.

Bill 2:57
For more information, just send an email to bill@recoveryafterstroke.com. I answer all my emails personally. And now it's on with the show. Duncan Campling welcome to the podcast.

Bill 3:12
Thank you for being here, man. I really appreciate it.

Bill 3:21
You have been the most keen person to get on the podcast now. I've had a lot of keen people to get on the podcast. You have just skyrocketed right through you are the keenest person.

Duncan 3:39
Yeah.

Bill 3:40
I really get excited when somebody goes out of their way to be on the podcast and organizes everything because it means that the podcast is valuable to them, and that I'm doing a good job. I'm gonna get stuck into it. First question that we prepared earlier was tell me a little bit about what happened to you?

Duncan Campling had Two brainstem strokes



Duncan 4:08
I had two brainstem strokes in March 2018. I'm 50 now, but I was 47 when they happened, I had a terrible headache. I called my manager at work to let him know I'm going to try and sleep it off as I often worked from home.

Duncan 4:30
I next remember having an out of body experience. from the ceiling. I saw my wife giving me CPR on my bed. My condition was eventually diagnosed as locked-in syndrome.

Duncan 4:46
Mine is from strokes but you can acquire locked-in syndrome from other things like ALS I'm partially recovered, but I still have a lot of progress to be made, locked-in syndrome is where you are completely paralyzed, but 100% cognitive.

Duncan 5:08
I can now move all four limbs, but they are very weak, especially my legs. That's why I moved around in a powered wheelchair. Locked-in syndrome is so rare, there's very little research done on it because it would only aid a small population.

Duncan 5:26
I'm often one of the few people with locked in syndrome a medical professional may encounter in their career. As you know, strokes are often caused by blood clots, or blocked arteries.

Duncan 5:40
But according to multiple CT and MRI scans, my strokes were caused by a thin artery in my brainstem. I also have the condition dysarthria. My vocal cords were unscathed from my strokes, but the muscles used for speech in my face and throat are very weak.

Duncan 6:01
People sometimes wrongly assume I'm mentally challenged, because I have issues forming words. Sorry, if my electronic speech is disjointed, and lacks enthusiasm. I drink liquids thickened with cornstarch as I still currently have swallowing

issues.

Duncan 6:22
Shortly after my strokes, I took liquid food directly pumped into a tube inserted into my stomach. Now I can orally eat most foods, including my favorite Indian food. I'm currently using an adapted Apple iPad with a speech synthesizer to communicate with you. I also use it to surf the web and post daily on Instagram.

Bill 6:52
Yeah, you do post daily, you're all over my Instagram feed. I can't get you off. And that's a good thing. That I'm not telling you to get off. It's interesting how I hear this voice and I see you, and even though I'd never heard you speak before, and I don't know you. I still say that voice and I'm thinking that's too English for you. Would you agree? That's a good English for you?

Duncan 7:29
Yeah.

Duncan 7:32
Awesome. How bizarre would it have been for you to have to experience seeing your wife floating above you? When you are having CPR to try and save your life and they were trying to resuscitate you? Very bizarre and strange. And did she come to you like an angel? Or was she just your wife going snap out of it?

Duncan 8:11
Wife.

Bill 8:12
Just your wife sitting there yelling at you telling you off?

Duncan 8:18
Yeah.

Bill 8:21
All right, Question two. How has brain injury affected others in your life?

Duncan 8:31
I lived in a nursing home about 10 miles from my two sons. Obviously, I'm unable to work and provide for my family. However, the biggest effect to other people is not being able to provide life advice in person to my preteen kids, and not being

there to shape their future.

Bill 8:56
Yeah, man, that really touches me because when I was going through my own stroke recovery, one of the first things I realized was that my boys as teenagers, they might lose their dad because you've got that serious, you know.

Bill 9:09
And because I had time in between bleed one and bleed two and then bleed three, which for me happened over about three years. I spent a lot of time making up for those things that I feel like I hadn't done properly or hadn't done enough of.

Bill 9:30
And that most of that stuff was me apologizing and saying sorry for being an idiot dad, or for not understanding you or for yelling and screaming at you when I had you know, not enough resources to express my myself properly. And I just resorted to being a caveman you know? Does the iPad support you in at least beginning some of those conversations and having some of those conversations?

Duncan 10:05
Yeah.

Bill 10:06
Yeah, that's good. Is that a sense of relief for you? Is it something that you want to continue doing I imagine?

Duncan 10:19
Yeah.

Bill 10:21
Yeah. Good, man. Awesome. I'm so glad. Isn't it fabulous that iPads exist? Isn't it fabulous that you and I can connect on the other side of the planet with this machine. And even though your vocal cords are not working properly in your muscles are not working properly. We're still having a proper conversation.

Duncan 10:42
Yeah.

Duncan Campling sharing his stroke journey

Bill 10:44
That's brilliant, man. All right. Question three. Why is it important for you to share your stroke journey?

Duncan 10:57
To give some motivation to other stroke survivors, and hopefully give them some energy when necessary. I'm not competing who's had the worst stroke journey, but daily life is often bleak for me. Telling my story also serves as a great workout motivation exercise, and is a huge mental release for me.

Bill 11:22
Yeah, so you explained that your life is bleak? Is that something that you feel it's bleak all the time or just sometimes?

Duncan 11:38
Sometimes.

Bill 11:38
So there are days and moments in the day which are not bleak or the opposite of bleak?

Bill 11:46
Yeah.

Bill 11:47
Is talking to me the opposite of bleak?

Duncan 11:53
Yeah.

Bill 11:55
Come on man, I hope so.

Bill 12:01
Brilliant man. Next question. What did you miss the most about the old you?

Duncan 12:09
It saddens me to know my old life is not waiting for me. I was understandably

terminated a week after my first stroke as I was by choice, an independent contractor. Also, I'm a 35-year electric guitarist, but only as a hobby.

Duncan 12:30
Playing the guitar post-strokes has not been possible for me as my fine motor skills are still weak and my hands feel very tight. To my horror, my house was sold 10 months ago. My retirement savings were liquidated early and spent however, I miss most not living under the same roof as my wife and boys. That and having an ice-cold coke on a hot day.

Bill 13:03
An ice-cold coke. Are you not allowed to have an Ice-cold coke anymore?

Bill 13:20
Sometimes?

Duncan 13:22
Yeah.

Bill 13:23
Yeah awesome okay. So your home was sold without your consent while you were out of action completely gone in that time? Or was it sold at a time where you were not involved in the conversation?

Duncan 13:37
My consent.

Bill 13:39
You did give consent. Okay, but still difficult and horrible situation. Have you had any other medical complications following your stroke?

Duncan 13:58
Online I'm perfectly normal, but in real life, I am quite disabled. To answer your question. I was hospitalized about two years ago for pneumonia and separately for a gallbladder infection which lead to sepsis, but nothing directly related to my strokes. Also, not that there are serious complications, but post-strokes I'm super sensitive to sharp sounds and low temperatures.

Bill 14:32
Yeah, I can relate to sharp sounds and low temperatures. Sounds are one of those

things that kind of makes my brain hurt. And temperatures are annoying because my left side is colder than my right side.

Bill 14:45
And it's always really challenging. Before I knew about stroke before, it happened to me. When I saw somebody in a wheelchair, I just assumed that they couldn't walk or move their hands.

Bill 14:57
I never assumed that there was additional issues that I had to deal with that I couldn't say. I never, for one moment thought there are people who are sitting in a wheelchair are just not able to walk.

Bill 15:11
I never understood that not being able to walk is a serious complication. And it causes its own complications as well. And hopefully what this interview will do for people is create the opportunity for people to have more awareness that people that are in need of being in a wheelchair or an electric motorized wheelchair have other complicated needs as well.

Duncan Campling Mindset during hard times



Bill 15:36
And we might not be able to see them. But we need to know that it's not just what you're saying. It's not just somebody sitting down in the chair. How are you managing your mindset to keep positive during the hard times?

Duncan 15:50
I tried to focus myself on making small gains, hoping that one day these minor gains will accumulate to more significant advancements, like walking and effectively talking. I also deliberately distract myself with music and Netflix.

Duncan 16:12
Like everybody.

Duncan 16:15
Yeah.

Bill 16:16
What's your favorite band?

Duncan 16:26
AC/DC

Bill 16:26
AC/DC Haha, that's my favorite band. Okay, what's your favorite album?

Intro 16:40
If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind. Like how long will it take to recover? Will I actually recover? What things should I avoid In case I make matters worse?

Intro 16:57
Doctors will explain things. But obviously, you've never had a stroke before, you probably don't know what questions to ask. If this is you, you may be missing out on doing things that could help speed up your recovery.

Intro 17:09
If you're finding yourself in that situation, stop worrying, and head to recovery after stroke.com where you can download a guide that will help you it's called the seven questions to ask your doctor about your stroke?

Intro 17:23
These seven questions other 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.

Duncan 17:42
Powerage

Bill 17:44
Powerage, nice, old school somebody that appreciates the back catalogue. I love it well done man I love powerage too. They were one of my favorite bands growing up and I've been to the Melbourne concerts probably five times or something like that amazing show. What was the hardest part of your journey so far?

Duncan 18:15
One of my biggest shocks was when I realized my multiple medications wouldn't repair me and we're designed to manage pain and anxiety. However, the hardest part of my journey was when the first ambulance came to pick me up.

Duncan Campling Flatlined in the ambulance

Duncan 18:33
I had completely flatlined. So I had no pulse. Also, I was totally motionless and paralyzed. The Medical Technician thought I had died and called my time of death in front of me.

Duncan 18:50
I wanted to stay on alive but nothing came out. Shortly afterwards, I was worried about being buried alive. Also, for the first three months, I was totally detached from reality and partially detached for 18 months.

Duncan 19:08
Pointing to letters on a piece of paper. I told my wife I created U2's sound and I co-wrote Sweet Home Alabama, even though I was four when it was written. I remember telling her all my royalties were directed to an untraceable Swiss bank account and not to worry as we'll go out for anything.

Duncan 19:35
I'm still amazed. I actually believe that. Also, I thought one of my therapists was shaggy from Scooby Doo. My biggest accomplishment was about one year ago when I could lean forward in my wheelchair. It allowed me to lean over a sink and brush my teeth. My old dentist would be proud of me.

Bill 20:04
That is hilarious. You thought you were the person who co-wrote Sweet Home Alabama a band called Lynyrd Skynyrd. And shaggy from Scooby-Doo was involved with your life? They must have been some serious drugs you were on man.

Bill 20:34
I love it. That's hilarious. I had a friend of mine who also had a serious stroke many, many years ago. And when he was recovering in hospital, his friends and his wife would read him the front page of the newspaper.

Bill 20:53
And at that time, unfortunately, in Melbourne, there was a big mob war happening. And there was a lot of people getting killed on a daily basis. And he thought that he was one of the people that was involved, the main mobster, and that their job, you know, was to run this war or be a part of this war.

Bill 21:16
And he would tell his friends like he was telling your family, he will tell them that. Yeah, he was with this particular mob boss. And they were, you know, running these scams, and they were doing things.

Lesson from a stroke



Bill 21:31
And he had been in the hospital for six months. (inaudible) It's so funny that side of stroke and that side of what the brain does, to, I'm not sure to amuse itself, or what does it do? Who knows? What has stroke taught you that you didn't expect?

Duncan 22:01
I assumed I was invincible before my strokes. I now appreciate being really healthy. Not that I was unhealthy before. I also limit my screen time and try to keep my mind healthy with word games, etc. I'm now on level 1890 of wordscapes.

Bill 22:26
Okay, so you're trying to limit your screen time? Are you having any success?

Bill 22:41
Sometimes. Yeah, I know what that's like. So do you still feel that you are healthy? Even though you got all these challenges that are related to the struggle, all these extra little bits and pieces that are there?

Duncan 23:03
Yeah.

Bill 23:07
How has the stroke impacted your feelings and emotions?

Duncan 23:13
I have all my thoughts and memories, pre and post-strokes. But my emotions are much more erratic now. For example, I sometimes laugh and cry at the same time. I assumed I'm losing it. But apparently it's a common side effect of strokes.

Bill 23:37
Yeah, me too. It's funny, the emotions, they come on really dramatically. And then they go. So in the beginning my wife couldn't really deal with it because I would watch a movie and cry at something cute, like a cat or something, you know?

Bill 23:56
And I didn't know how to tell her that I'm not sure why I'm crying. I'm just crying, you know. So a lot of stroke survivors struggle with that. Especially. It seems to me men seem to struggle with that more because we've always been told not to cry, and we've always been told to be tough and to get over it.

Bill 24:16
So it's interesting that it's a difficult thing for people to handle. But it does get better. I found that it does get better. But sometimes it's still there kind of just pops up out of nowhere. You have a similar experience. It's slowly getting better?

Duncan 24:38
Yeah.

Bill 24:39
Awesome. How does intimacy play a role in your life these days?

Duncan 24:46
For me, relationships have obviously been restricted to online contact during the pandemic. Also, I have strained a few friendships post-strokes but I always reach-out to remind them, I'm still here. However, I remain positive about the future.

Bill 25:09
Yeah. COVID complicated stroke recovery for so many people, it completely changed their ability to continue to see people and get out and about and grow their networks or still continue to hold on to their networks. And that's a big issue. So your friendships with your friends have become a little distant, would you say?

Duncan 25:44
Yeah.

Bill 25:45
It’s a common thing. And it’s something that I went through as well. And I went through the stroke in times when there was no COVID. And still people became distant because they didn’t know how to be around me and how to catch up with me and what to talk about and what to say and what to do.

Assistance required

Bill 26:10
So it’s more about them than it was about me. So it’s about maybe I’m not sure, Duncan, if the right word is their lack of frames or references for how to act around people who are unwell. Yeah, it’s very common. Next question. What help do you receive at home for things like showering and toileting?

Duncan 26:45
I currently require considerable assistance for both. Although I tried to be as independent as possible and brush my teeth with an electric toothbrush and partially shave with a Benjamin, similar to hair clippers. My father, who lives in England also had a stroke last year, but he’s currently able to move from his bed to a wheelchair unassisted. So I assume he’s able to transfer from his wheelchair to a toilet seat on a system too I hope to be that mobile one day.

Bill 27:26
Yeah, that’s a good thing to aim for Man. That is an awesome thing to aim for. Your dad had a stroke as well. Same kind of stroke?

Duncan 27:40
Yeah.

Bill 27:45
That’s interesting. All right next question. What is the best thing that has come from your stroke experience?

Duncan 27:57
The best thing is probably having more time to connect with friends. Although COVID-19 has limited that to Instagram, and email, I like sharing with my friends,

my mildly entertaining posts and messages.

Bill 28:17
Mildly entertaining, that's a good description. No I do enjoy our interaction on Instagram. Obviously, when this conversation goes live, what I'm going to do is put all the links to your Instagram so that people can jump on board and connect with you as well.

Bill 28:45
Because we do have, we ask some serious questions on Instagram, and people do interact. And we have really big insightful conversations. And I think they're a great place for stroke survivors who are listening to come to to get a little bit of extra motivation perhaps or a little bit of extra understanding and feeling a little bit more normal. All right. Next question. How has COVID interfered with your recovery? I know we briefly touched on it in our conversation about that

Duncan 29:28
As I live in a US nursing home under strict quarantine conditions. All external therapy has been unfortunately halted for me until the scare over the virus has subsided. Internal therapy is also on pause, but that is for medical insurance reasons.

Duncan 29:51
In my experience, therapy dramatically diminishes after one year and next month will be my three year stroke anniversary. I'm my own therapist, obviously, I have no training. But I had an idea of good form.

Duncan 30:10
Apart from video communication, I've only seen my wife and kids twice since COVID-19 began. And I haven't left this building since March of last year. I know the pandemic has impacted everyone, but I've only been allowed to leave my room about 10 times.

Bill 30:33
So you've only been allowed to leave the room 10 times to go outside and experience fresh air?

Duncan 30:43
Inside the building.

Bill 30:47
Yeah. That would be tough. But obviously, it makes sense to try and keep you guys safe. Yes, we want to make sure that we keep you safe. I get it. Thank you for going to all the trouble and being here. I really appreciate it.

Duncan 31:07
Thanks so much for your excellent interview technique. And of course, your time. I really appreciate it. I'll say

Duncan 31:21
Goodbye

Bill 31:26
You're welcome. You know what? How did you know I was gonna be an excellent interviewer? You're so polite man. Hey, goodbye to you enjoy the rest of your day.

Intro 31:51
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Intro 32:08
Opinions and 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.

Intro 32:18
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Intro 32:30
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