

THE CHRONIC ILLNESS RECOVERY PODCAST

Episode 29 - The Hardest Part About Chronic Fatigue Syndrome

Hello everyone, and welcome to the CFS Health Recovery Podcast. I am your host, Toby Morrison, and in today's episode we are talking about the hardest things about chronic fatigue syndrome. Before we get into it, this is a really important topic and I need to pre-frame this by saying that, whilst there are some really extremely hard parts about chronic fatigue syndrome, which we will talk about today, there is hope.

We see every single week, people improving the quality of their health, the quality of their life, and simply put, people from all around the world in over 54 countries, all age brackets from as young as 8, all the way up to 84 plus- shout out to our older members too- you know, we see every single week that people can get better, but I really do think this is an important topic to talk about because if this is new for you, or you are down the line and you're feeling lonely, you're feeling isolated, and you feel like you might be going a little bit crazy, this episode is going to really confirm some of the hardest parts about chronic fatigue syndrome.

Before we get into that, I wanna share win of the week. Now this win of the week goes to a bunch of clients. Every single week inside our podcast we share win of the week, and this week is more of a general one. I want to share some of the things that are happening for our members, in terms of the progress and the insights they're having. One particular win this week, which I thought was fascinating, was regaining healthy weight. So, you know, one of our members lost a bunch of weight when they first became ill, and it's taken several months- if not years- to regain that healthy weight. And now they're at a better weight than they were before they got sick. So that's a huge, huge win in my eyes, and it's a good sign of health.

Another one is healthy poos. You know, we talk a lot about, in our program about healthy digestion, and we've noticed a lot of members lately have really noticed their digestive system's getting better. They're having healthier formed poos, and of course they're feeling better because of that.

We've got members who aren't getting sick as much with colds and flus, or

when they do get sick, they bounce back really fast compared to; maybe it took them 4 weeks to recover, now it's only taking them 1 week. So there's just some wins and I'm not gonna say names today, I just wanted to share some general wins that I think are really cool and maybe you haven't thought about that.

Lastly, I want to give a shout out to my lifestyle integrators, my lifestylers. These are people who are in our lifestyle integration program. They're beyond initial recovery focus, and now they're focusing on integrating back into life.

They're starting to move into life more. And what I noticed on that call the other night on our private coaching call, was that everyone's face had coloration. What I mean by that is that there was this certain glow in their face. There was this certain amount of health and wellbeing in their face, in their facial expressions, in the coloration of their skin. And I actually said to all of them, I would love them to go back to their first initial call recording, and look at the difference between the coloration in their skin and just notice what they see. But it was definitely profound for me because I was looking back going, wow, you know, I've been working with some of these people for over I year, some of them even 2 years, and it is a day-and-night difference.

So you might be thinking, "oh, that's interesting!" We've gotta pay attention to these things, because if we're not aware of it, we don't see it. And if we don't see it, we don't believe it. And these are just some of the things that we've been seeing inside the mentorship program at the moment.

Without further ado, let's get into it. The hardest part about chronic fatigue syndrome is many things, and one of the hardest parts about chronic fatigue syndrome without really having to say it, is the fact that it's really an invisible illness. You know, when you break your arm or you break your leg, you go to the doctor, the doctor gives you a cast, they put it around your arm or leg, your broken bone, and you walk out with this physical object that says to the world, "I'm in pain. I've hurt myself." And then the world responds with sympathy and empathy. It says, "oh my God, are you okay? What happened? Is there anything I can do?" The problem with chronic fatigue syndrome is that no one can see it, at least not initially, and you might look fine on the outside, but on the inside you're really, really struggling.

And I think the hardest part about that is the fact that the outside world cannot see it. You are so isolated. But on the outside, in the physical world, people can't see it. And so you get very little empathy, you get very little understanding, and usually you get a lot of misconceptions.

"Oh, you're just not motivated. You're just depressed." You know, I think one of the biggest problems that the outside world that I see, people who aren't experiencing chronic fatigue syndrome, is that they say, "well, isn't chronic fatigue syndrome just all in your head? Maybe you just need to push yourself more. Maybe you're not trying hard enough. Maybe you need to be more positive and just smile more!" Argh! You literally want to slap that person in the face! And if you are one of those people who is trying to support someone with chronic fatigue syndrome, and you're saying these kinds of things, maybe your intention is good, but just understand how hurtful that can be when someone is really in the depths of despair and really, really, struggling.

So number one is, it's an invisible illness. It's not like a broken bone that you can walk around and go, "look at me. I've got this cast on my arm. Please go and put your name on it and write something on my cast," right? It just doesn't happen like that. Which leads into the second part of the hardest part about chronic fatigue syndrome, is friends.

There is just such a lack of understanding and knowledge around chronic fatigue syndrome, and when you go through this process and experience, the hardest part is that your friends don't understand. Not only that, that you can't actually go and do what you used to do with your friends. And so there becomes a disconnect. And it's horrible, like it literally is so emotionally painful. It's like a separation. It's literally like a relationship separation, because you can't do what you used to be able to do, and your friends don't understand, and then you feel like you have to make excuses. And you have to excuse yourself. You have to over explain yourself and you feel really guilty. That is one of the hardest parts about chronic fatigue syndrome.

I said friends first because, you know, sometimes friends are our outlet away from our family. But when the friends go, the family comes in as the first point of call. And the hardest part about chronic fatigue syndrome, is that there's a real struggle and sense of loss within the family. On one hand, your family just grieve the person that you were; on the other side, all they want is for you to get better. And so there can come a sense of pressure with that to the person suffering. You know, there's almost like this dragging the dog out the door when the dog is pulling and saying, "no, I don't want to go, I'm not ready, or I can't do it." But the person is like, "come on, come on. You need to do this." And there's this pressure.

I think one of the hardest things that people have to go through with chronic fatigue syndrome is the sense of guilt: letting their family and friends down. It's such a heavy burden that one places pressure on themselves when they're going through chronic fatigue syndrome, to get better fast because they don't want to let their family and friends down. And can you imagine how hard that can be on the person dealing with this?

I always say that, you know, there's usually suffering on top of suffering. And

what I mean by that is, firsthand suffering is the pain and the the symptoms and the physical suffering that you're experiencing with chronic fatigue syndrome. The secondary suffering that comes on top of that is these things of guilt, sadness, heavy emotion that often comes as a secondary nature to experiencing something like chronic fatigue syndrome.

And so, you know, one of the biggest things that I know for a fact, a lot of our members feel this, and this is why we brought on a guilt expert to run a "how to let go of guilt" workshop, which has just, oh, it has given so much freedom to so many people in our program around the world, because they no longer have to experience guilt anymore. But it's definitely a process. People, when they first go through this, it's like the heaviest emotion that they feel.

I think the hardest part about chronic fatigue syndrome is going to the doctors. You know, I'll never forget when I finally got diagnosed with chronic fatigue syndrome when I was a teenager, and before that, it was a 2 year struggle of literally going from doctor to doctor, blood test to blood test, trying a million different therapies, trying the most alternative, weird, wacky therapies you can imagine, my family and I tried it. And when we finally found a specialist at Olympic Park in Melbourne, Australia, he sat us down- and you know this was gonna be one of the best days of my life, I thought, and we're finally gonna get an answer. And we did.

I remember going into his office and I was, you know, extremely deconditioned at this point in my life, I had lost 20 kilos of muscle mass. I could barely function throughout the day. I was sleeping 15, 16 hours a day, and I was so severely ill. And I remember, I just needed an answer. And we sit down and after he'd ran all the tests and he got us back in another time, he sat us down and he said, "you've got chronic fatigue syndrome."

And I was so excited. I was like, "for the first time, I know. Now I've got an answer!" You know, before that I didn't know what was wrong with me. There were so many things going wrong with me, but I just didn't know what it was. I couldn't put my finger on it. And this specialist said, "yeah, you've got chronic fatigue syndrome." And I said, "well, great. So what do I do now?" I was such a proactive thinker that all I could think about was, "well, what's the thing that I need to take to get better?"

And he said, "there's nothing. There's no pill, there's no medication. You kind of just have to go home and rest, but there's not much you can do." And I remember in that moment, I went from the highest amount of happiness and just confirmation- "finally we've got an answer"- then within minutes feeling so deflated. It hurt so much that I literally felt like my heart was gonna tear in parts. I just couldn't believe that, "what do I do now? There's nothing left." And I

remember going home that night- and for those of you who know my story, I was a basketball player before I had chronic fatigue syndrome- and I remember going home, and I was so frustrated that as I walked into my bedroom, I picked up my basketball shoe and I just threw it as hard as I could against the wall, and I just screamed and cried, and cried, and cried.

I was just so upset and sad. Why me? Why me? Why does this have to happen to me when I'm a good person? There are other people in the world who deserve this more than I do. And even to that point, no one deserves to experience this. It's horrible. And of course, you know, a long story short is that I picked up the pieces and it took another kind of six months to really figure out, well, you can get better, it's just that there's no pill for you to take to get better. And I'm not gonna go into that story today because I want to stay on our topic, but one of the hardest parts is the doctor, to doctor, to doctor to doctor; the bouncing of doctors. And this is not a discredit to doctors.

I think there's some absolutely wonderful doctors in the world. And I constantly give a big shout to Dr. Lionel Lubitz. He was the head of Royal Children's Hospital, and I was a patient of his. He was the one that said, "you know, it's possible, but it's not a quick fix. It's not overnight, but you are gonna have to do some things to help yourself here." And so the concept of the baseline really started from there.

Many, many years later after I recovered and then, you know, I realized I wanted to make sure that no one else had to go through this, I went back to Dr. Lionel Lubitz, and I said, "can you look at this program for me? I've just created it. I want your advice." And he went on to write the foreword for my book and has been a huge advocate over the years to our work. And so, you know, there's some brilliant doctors in the world. But there are many that are not educated. There are many who don't believe that chronic fatigue syndrome is even real. And can you imagine how insulting that is and how hard it would be for someone who is struggling so much to go to a fricking doctor's clinic and to be told there's nothing wrong with you? "Good luck!"

It's excruciatingly painful, and one of the main reasons why CFS Health was born was because of the pain and suffering that I went through, before I realized that I could do things to help my health and life improve. And you know, that pain and suffering was so excruciatingly deep that it was a huge driving force for CFS Health to be born, and CFS stands for- hopefully you know, now!- Choice, Freedom, Success.

It doesn't stand for chronic fatigue syndrome. And so, if you're going through this right now, just know that it can get better. But know that you're not the only one who's feeling this way when you're going from tests to doctors, to this, to that, to being told that there's nothing wrong with you, to being told that there's

nothing you can do, that you're making it up, maybe you're just depressed, maybe you need to be more motivated, maybe you just need to sweat it out more. There's been some horrible things said in the world to people with chronic fatigue syndrome and it needs to stop.

Moving into our next topic of the hardest part of chronic fatigue syndrome, is literally the unknown. Not knowing what to do, especially when there's been no education or awareness around this. And there's this feeling of uncertainty, of going, "what do I do next? I've almost tried everything, and nothing's worked." And you know, you go from quick fix, to quick fix, to quick fix, because the culture said to us that when you get sick, you go to the doctor, you take a pill, you get better. Unfortunately that doesn't happen with chronic fatigue syndrome.

And lastly, the guilt and the grief. On one hand, we spoke before about the heaviness that comes with feeling like you're letting people down, feeling like you're letting your family down, your friends down, you've let yourself down. You haven't, but that's how you feel. You really feel that, and it's such a heavy burden to carry. I imagine it to literally putting on a backpack and literally filling your backpack with as many heavy rocks as you possibly can. And then you put the backpack on, and then now you're walking around with those guilt rocks every single day, and that is an exhausting, deflating process.

And then grief. I think the hardest part that everyone has to go through in their recovery in order to recover, is to let go of their past. And it is so hard when you have tied your whole entire life up to a certain identity, that when you no longer can be that person, your life feels like it's falling apart, and you so badly want to hold onto that part of you. "Please, please, no, I need it back!" And you're chasing your old life back, and you're grieving your old life. And again, it's a normal process. It's part of the healing process. In fact, it's necessary to let go of the old you, and build the new you. And just know that it's totally okay if you are grieving the old you. And also know that it's very hard to drive forwards when we are looking in the rearview mirror. Very, very hard to drive forwards and focus on where we're going if we are constantly looking in the rearview mirror of the past and looking behind us.

But know it's normal. The whole purpose of this episode is to bring awareness to the five hardest parts about chronic fatigue syndrome, because you might be experiencing this right now, and maybe you just need the validation to know that what you're going through is extremely normal and very, very real.

Stay tuned, at the end of this video, I'm gonna share with you some really great tips and some free trainings that are gonna help you with your recovery. So don't worry, we're not leaving on a heavy note. We're gonna leave on a nice light note that you can actually focus on some proactive, practical things that

can help you start to move forwards!

But I just want to say, keep going. I know what you're going through is extremely hard and extremely difficult. And I know for a fact that it can change. I've seen some of the worst cases in the world get better. I've seen some of the worst cases in the world, who have been told that they're not gonna be able to get better, they've seen the best doctors in the world, they've tried the best 'treatments' in the world, and then eventually over time, by doing the right things at the right time, they have gotten better over time. And so, my wish for you is that you just focus on improving the quality of your health and the quality of your life, and even if it improves five or 10%, it is worth it. But hang in there.

The countless stories that I have is just incredible. I was sharing this story the other day just before, and I was talking to a friend about doing seminars, and we ran seminars across Australia and overseas, and I remember one particular seminar I was running, and there was probably like 40 or 50 people in the room, and there was this young girl and her mum. Mum had dragged this young girl into the seminar because she was so ill with chronic fatigue syndrome and they really, desperately wanted some help. And the girl was too ill that she couldn't actually sit up. She had to lay on the only couch we had in the seminar, and she felt really ashamed.

And I actually said in front of everybody, I said, "you've gotta do you. So if you need to lay on the couch right now, if you need to close your eyes, if you need to have a nap, there is no judgment here. All right? No judgment whatsoever. Do what you need to do."

This was when the online program launched in 2013, over a decade ago, and the craziest thing happened. About two years later, I get a Facebook message from this young-ish girl, and the youngish girl left a voicemail, a voice message, and she says, "hi, Toby. I don't know if you remember me, but I went to your seminar in Hobart, Australia, and I was the girl that was laying down on the couch and was so sick that I couldn't sit up. I just wanted to thank you so much for your work and your program. I'm now going to University, I'm as healthy as I've ever been, I have a boyfriend, I'm exercising, and I'm just having so much fun, and I just wanted to thank you so much for your work." And, you know, I forgot about that story until the other day when I was sharing, talking about seminars to a friend of mine. And, there's just so many countless stories of those kinds of things happening.

Now- was it overnight? Was it a quick fix? Was it a magical thing? No! It took work, right? It took work from the individual, but it's definitely possible. So stay tuned, I'm gonna give you some really helpful trainings and tips in a moment.

For now, sending you a ton of love, hoping this was really helpful. And again, feel free to share it, hit the like button, share below if this was helpful for you. You know, share below in the comments if this was helpful for you. And of course, we'll see you very soon. All the best for now.

Hey, I hope this video was really helpful for you. If you haven't already, please hit the like button and feel free to leave a comment: what was your takeaway, your insight from today's video? It's really helpful to actually write your learnings down. We seem to embed it better and it seems to help us move forwards with life. Here are three ways we can help you right now, whenever you are ready: the first way is make sure you add yourself into our free information recovery group on Facebook. We'll leave a link in the description below. It's a really supportive, encouraging place. There's no negative venting, you can ask questions to other people. There's something like 7,000, 8,000 people in there right now, and I'm sure by the time you're watching this video, there's even more. So go over there right now. We share success stories, we share our latest free trainings that come to the public, and we always share upcoming information about upgrades inside our program, and also when we offer free webinars or free information nights that can further help you with your own recovery.

The second way we can help you, which is one of my favorite, is through all our free trainings. We're gonna leave a link in the description with our favorite free trainings that we know can help you start your recovery, whether that's through our baseline training, which will help you stop pushing and crashing, our three stages of recovery, to figure out exactly where you're at and know what to do next, or my favorite, which is our guest panel workshop, which was actually exclusive for our members. It was so damn good that I actually asked them, "can we share this to the public?" They all said yes, all five of them. So thank you, past members! They share their five recovery secrets and it's really powerful. There's tears, there's "aha" moments, there's real key insight and inspiration. And so whether you're a 1/10 and you're really struggling right now, or whether you are further along in your recovery journey and you are integrating back into life, we have you covered.

The third way we can help you is through our actual paid online recovery program, the Mentorship Recovery Program. And if you are interested in getting proper help, a holistic, comprehensive plan, professional coaching from the best coaches in the world- whether that's with mindset, movement, nutrition, restorative movement, reconditioning, integrating back into life, integrative medicine, baseline, structure, routine, accountability, all things health and life-feel free to apply for the program today. All you need to do is click on the form, cfs health.com/form. Fill out the short two to three minute form application, and the team will be in touch with all the details that you need to know about the program via email.

So make sure you check your spam folder for all the free trainings. If you've sent through an application, please be patient. My team are real people, okay? They're not robots. So if we don't get back to you within seconds or hours, it's okay. We will get back to you! If you don't hear from the team within two to three days, that means that it's basically gone to spam or junk and it's gone missing, so please send a follow up email to the team at info@cfshealth.com. If you have any questions, go check it out, but I would highly recommend adding yourself into the free group right now, go click on that link in the description. Go download all the free trainings. Honestly, the whole reason why this whole thing started is because when I went through this myself, it was so painful and so excruciating that I didn't want anyone else to have to go through it.

And some of these free trainings are so damn valuable, back then I would've paid thousands of dollars for them. We've had so many comments and emails and posts saying, "oh my God, the baseline training was a game changer for me." "Toby, I've been doing this now for three months and I'm feeling so much better, my symptoms are decreasing, I've got more stamina, I've got more energy, I'm able to do more things."

So, you know, whether you are learning from us and consuming our content through our free format, I'm so stoked. Whether that's in our paid program, I don't really care either way. All I want to make sure is that you are moving forwards, you are starting to really implement this work. And that's really what it's all about. Once we implement, we make change, and we start to move forwards. Sending you a ton of love. Of course feel free to consume as much of the YouTube videos as you like. There's so many really, really great ones, new and old.

Sending you a ton of love and speak to you very, very soon.

All the best for now.