INTRO:

[THEME MUSIC]

JOHN

Hello and welcome to The Medical Mind. I'm John Moe. I'm an author and podcast host and I interview people and write about mental health.

KEN

I'm Dr. Ken Duckworth, a psychiatrist and the Chief Medical Officer of NAMI. The Medical Mind is a podcast about mental health treatments and the people who benefit from them. This special episode is co-presented by SMI Adviser, a Clinical Support System for Serious Mental Illness; and by NAMI, the National Alliance on Mental Illness. SMI Adviser is funded by the Substance Abuse and Mental Health Services Administration and administered by the American Psychiatric Association.

JOHN

These podcasts include the real-life experiences of people with mental illness and family members. Some of the content includes discussions of topics such as suicide attempts and may be triggering. To receive 24/7 crisis support, please text "N-A-M-I" to 741741 or call the Suicide and Crisis Lifeline at 988.

John: [00:01:12] And Ken, we are making this show in order to maybe demystify mental health a little bit and show just how much of a connection there is between the science of the treatments and the latest discoveries about treatments and regular people just living their daily lives. So, we're going to be talking with some experts and we're going to be talking with some regular folks as well. [00:01:38][25.9]

Ken: [00:01:39] Lived experience experts, because if you've *lived* with borderline personality disorder for 40 years and have been using DBT for 20 of them, you know what it's like. So, I love this concept of talking to one of the national experts in the treatment and a person who really can tell us a little bit about the experience of it. [00:01:59][20.5]

John: [00:02:00] Yes, it's an excellent use of expertise, because expertise can be gathered in a number of ways and we'll be getting a wide scope of expertise on this particular show. We've talked about this a little bit before, Ken, but we got into this for some personal reasons. My older brother Ric died by suicide after a

lifetime of mental illness. And I took up the cause that if we can talk about this stuff more, more people can be helped. If we talk about it less, if we shame it, if we embrace stigma, then more people will suffer and we'll lose more people. So, let's make the sensible choice and be more open about mental health. I understand that you got into it for very personal reasons as well. [00:02:43][43.3]

[89.8]

Ken: [00:02:44] So, you know, there was never a psychiatrist in my family and I actually didn't know what a psychiatrist was. But when you love somebody like my dad, who was a charismatic, gentle, fun man with very severe bipolar disorder, was probably hospitalized 25 times in his lifetime. And you can't talk about it. The amount of shame and secrecy and pain that that develops. So that's how you create this psychiatrist. I was actually more interested in every other thing. I was not a science kid. But when you love somebody the way I loved my dad and you could see how much pain this illness was causing him and those around us, I said, Oh, what the hell, I'll try to go to medical school. Knowing that I was not a whiz at science and I suck at calculus. [00:03:28][43.8]

John: [00:03:29] Well, there you go. You know, you play the hand that you're dealt. Today we're going to be talking about dialectical behavior therapy.

And I'll give you the definition from the Cleveland Clinic: dialectical behavior therapy is a type of talk therapy for people who experience emotions very intensely. It's a common therapy for people with borderline personality disorder, but therapists provide it for other mental health conditions as well.

Dr. Blaise Aguirre is going to join us to walk us through what that treatment is. And then we're going to be talking with Cathleen Payne, who is, as you say, a lived experience expert, somebody who has benefited greatly from dialectical behavioral therapy. But let's set the table a little bit first. I suppose you can't talk about what DBT is without talking about who Marcia Linehan is. [00:04:02][33.1]

John: Marcia Linehan is a psychologist at the University of Washington and the creator of DBT.

Ken: [00:04:03] Marcia Linehan is a genius. She went through her own mental health experience, which she discusses quite openly, and she basically says in her memoir, I went through hell and I decided I was going to help people get out of it. Her approach was to integrate the concepts of Zen Buddhism and behavior therapy, the idea that there's a dialectic of both acceptance and change. Radical acceptance, interpersonal effectiveness. These are core concepts that she

introduced. And DBT has become a transformative force in American mental health. We used to be taught not to tell people that they had borderline personality disorder because we didn't really have a treatment. And it was easy to dismiss somebody because the clinicians felt helpless. Marcia Linehan invents the treatment that works. It reduces the outcome of suicide. It helps people cope better to build beautiful lives. Very frequently, the long-term outcomes are quite good. And it was her genius. Literally going to Asia and studying in a monastery in Germany with a with a priest for a few years. I mean, she really took this acceptance thing strong and integrated that with her Ph.D. in psychology and her tenacity around researching ideas. She has said, if you can come up with a better idea than DBT, bring it on, I'll practice it. She's an exceptional person and resource and I think really is just a national treasure. And what she has given us in this treatment, which is coping skills-focused, helping people replacing behaviors like self-mutilation or cutting, or drinking excessively, to calm dysregulation. This feeling of biologically overwhelmed emotion. [00:05:59][115.8]

[115.8]

John: [00:06:00] And who benefits the most from this? Who's an ideal candidate to be helped by DBT? [00:06:06][5.3]

Ken: [00:06:07] Well, a person who has borderline personality disorder. So, this is the disruption, this dysregulation, unstable relationships, intense mood changes, butt not like bipolar disorder over weeks. It's within minutes. An unstable sense of self-esteem, self-cutting, self-harming behavior. This is thought to be largely a biological reality that some people are born with. Some people who have traumatic childhoods are at higher risk of this. But there exist people with borderline personality disorder who had really nice, happy childhoods. That's who the treatment was designed for. Marsha also feels it's helpful in other areas, and they're studying other things. But people who are chronically suicidal, they're a good candidate. People who are struggling with addiction and have self-esteem problems could be candidates for this. It's incredible. And in the NAMI book that I just wrote, I ran across three or four people who said DBT changed their lives. [00:07:13][66.0]

[71.3]

John: [00:07:14] Ken, we're going to listen now to a conversation that you had with Dr. Blaise Aguirre. He's a child and adolescent psychiatrist and assistant professor at Harvard Medical School. He specializes in the treatment of borderline personality disorder. [00:07:28][13.4]

Ken: I've known Blaise for years, he's a lovely man and a wonderful teacher about DBT. We connected with Blaise over Zoom from his office in the Boston area.

[MUSIC BUTTON]

BLAISE INTERVIEW

BLAISE: [00:02:21] It always surprised me that people wanted to die. I couldn't quite understand it. And, you know, I knew that people had suffered tremendously with cancer, with other types of illnesses. But this idea that a mental illness would need someone to want to die was very confusing to me. I found a lot of joy in living. And but one of the things that started to happen when I started to meet people who were very suicidal was most people who live don't, you know, spend that much time thinking about why they live. But many people who wanted to die spent a lot of time thinking about life. I actually found that they were some of the most fascinating people in the world. I thought, there's so much in you and you have so much to give. [00:03:19] [00:03:41] But the problem was that they would leave my sessions not knowing what to do. and they felt very understood, but they didn't know what to do. And then some of them said that they were doing this thing called DBT. And what they liked about it is that DBT provided them with actual practical ideas about what to do, so that whereas I was striving for something called "insight" that we talk about a lot, that that didn't seem to be reducing the suffering or of getting them away from wanting to die. What DBT did is both provided this forum of switching from-- Yes. Having some insight, having some compassion, but also in the moment, doing something about it. So, it was because my old methodology wasn't working that I decided to switch. [00:04:49]

KEN: [00:05:09] I want to switch gears a little bit. Let's go to the big picture of radical acceptance. You know, this is a great concept. Marsha Linehan won a NAMI award and she gave a great talk on radical acceptance, which, you know, was new to a lot of people in the NAMI community. I wanted to ask you a little bit about that, how you think about it. Do you discuss that with people overtly or is it just kind of in the air of DBT? [00:05:36]

BLAISE: [00:05:38] We talk about it front and center with our patients and with our therapists. The idea that this present moment was just as it is, was actually very new to me. I mean, I had never understood this concept of radical acceptance. So. If you imagine that you're stuck in traffic, well, in that moment,

you're stuck in traffic. If you like that you're stuck in traffic, it doesn't change that you're stuck in traffic. If you hate the fact that you stuck in traffic, it doesn't change the fact that you're stuck in traffic. And where I think a lot of people were going wrong with this is that they acted as if this moment was going to persist for eternity. So, I will always be stuck in traffic. I will always hear voices. I will always be depressed. And so this idea of just saying, in this moment, this is as it is and wishing it away or wishing it were not so, doesn't change it. So, if you can bring a state of mind that is one of acceptance rather than of fighting and rejecting, in moment at least, you would become more effective and less stressed out by accepting. Again, different from liking or not liking. Because that did not change the moment. [00:07:07]

KEN: [00:07:07] Closer to the Serenity Prayer, on steroids, for mental health. You accept what is. [00:07:11]

BLAISE: [00:07:11] Exactly.

KEN: When Marsha Linehan gave her speech at the NAMI Awards, she talked about, the core problem of both suicidality -- just as you began with, Blaise-- and this idea of dysregulation. Can you develop the idea of what dysregulation is? [00:07:29]

BLAISE: [00:07:34] As human beings, we are emotional beings. Without those

emotions, there's no way to survive as human beings. I mean, if you're an earthworm, you probably don't need that many emotions. You dig around the earth and bump into another earthworm and whatever. [00:07:59] As human beings, emotions are the alarm system for the human body and the human mind to tell us something is going on. You need to be scared. You need to be sad. You need to be in love with it, whatever it is. And those emotions communicate something to ourselves, communicate something to somebody else, and propel us to action. [00:08:30] [00:08:32] Let's just imagine emotions as a fire alarm in a building. You know, the fire alarm goes off and people leave the building. And that all makes sense because you don't want to be consumed by the fire. For some people, a couple of things happened. One is that the fire alarm goes off all the time, whether there is a fire or not. And so what happens is they're always responding to this alarm bell. For some people, this alarm is really loud and it's very distressing [00:09:10] [00:09:14] So the idea that we all have emotions, but some people have them much bigger than others and some people have them much smaller than others. That's still not a problem. The problem is if the behavior that ensues is dependent

on that state. So, if I kept living leaving the building because I wasn't able to discriminate between an alarm that is just a test alarm versus an alarm that's an actual fire, that would be problematic. So, some people that we see, when they have big emotions [00:09:48] [00:09:52] they decide they're not going to go to work. For all of us, those of us who don't respond in that way, we go to work whether we're upset or not, because we have to do that. [00:10:02] So, it's this idea not so much of having big or small emotions, but behaving depending on mood. The other part of it is saying, I need to be able to narrow my mood range to something that's much more [00:10:21] [00:10:21] manageable, [00:10:23] [00:10:24] You've got to regulate before you can reflect. If your brain is on fire, if your emotional house is on fire, it's very, very difficult to think. So those were the two ideas: 1) very big moods, 2) being able to regulate those moods. And 3) not behaving simply on moods. [00:10:44]

KEN: [00:10:45] It's so interesting that you trained in psychoanalysis--again, a focus on being understood and insight--and you transition to a concept that's much more skill-based to help you deal with dysregulation. [00:11:00]

BLAISE: [00:11:06] it seems to me that the psychoanalytic process is one that requires an intact prefrontal cortex, a lot of capacity for reflection. But the problem with many of my patients is that they're so dysregulated that they cannot think. And if you cannot regulate, you cannot reflect. [00:11:30]

KEN: [00:11:50] Right, I can't have an intellectual discussion. [00:11:52]

BLAISE: [00:11:52] Exactly. I think what happens with a lot of the psychoanalytic process, what some of my patients are dissatisfied with is that they feel that they're put into a position where they're being forced to use a part of the brain that they cannot because they're so overwhelmed by strong emotions. [00:12:09]

KEN: [00:12:28] let's say somebody is fortunate enough to find an opportunity to work with you or someone else like you. What's DBT look like on a week-to-week basis? [00:12:38]

BLAISE: [00:12:46] you want to make sure that the treatment that you are offering is a treatment that the person needs. If you look at the full DBT treatment, it's a very big treatment with a lot of requirements. And, you know, I don't think that the majority of people, even the majority of people with conditions like for like borderline personality disorder, need the full DBT treatment. If you have an asthma attack, you might need an inhaler, but you don't need to go into

the intensive care unit. So, two people who have asthma, one ends up in the intensive care unit, the other one just needs an inhaler, an outpatient person. [00:13:26] [00:13:28] But let us assume that this is somebody who is really struggling with controlling their emotions with suicidality, with self-injury, with disrupted relationships, disrupted cognitions and things like that, and that we agree that this person needs the full treatment. There are a few components. The first component is a teaching component. And this is very manualized. It is the teaching of the skills in the same way that a kid would go to a class to study mathematics or geography or biology. So what are the core skills of DBT, which are about regulating emotions, tolerating distress, mindfulness, and being more effective interpersonally? And that is taught to everybody who's in that skills group. That's a group setting. Together with that, there is an individual therapy that is done by a DBT therapist. [00:14:26][00:14:33] Individual therapy contextualizes the therapy to the patient's individual life. So, if somebody is not having problems with the relationships, then the individual therapist won't be looking at that as a problem. But if they're having problems with substance use or with emotional regulation, they will see how these impact the patient, etc. [00:14:56] [00:15:57] There are two other component parts. As DBT therapists, we are coaches, and we want to coach people in the moment that they need it. When I was doing more psychoanalytic training, my patients could only come and see me on the day that they came to see me. They didn't have any intersession contact with me. Whereas in DBT, if a person is struggling at 6:00 on a Friday night, I want to help them in that moment. [00:16:26] [00:16:34] And then finally, because working with suicidal patients can be very emotionally draining for therapists, those of us who do DBT sit together in a consultation team, which is with other DBT therapists, and we talk about the work that we do so that we can stay in the game of helping patients. [00:16:55]

KEN: [00:16:55] This is creating a community of support you that you can do what is very challenging work.

BLAISE: Exactly.

KEN: So, you mentioned these four modules. Let's just take a minute and walk through them. Let's do mindfulness first. [00:17:07]

BLAISE: [00:17:08] Yeah, this was a surprise to me when I first heard about mindfulness in terms of psychiatric care. But this idea that they're paying attention to the phenomena that arise in the present moment, whether it's a sensation, whether it's a thought, whether it's an urge, and that you could

observe your own mind at work so that I can observe the fact that I'm having a thought. I can observe the fact that I'm having an urge. And the reason why that was so important is because for many people who have no capacity for mindfulness or little, we see a lot of impulsive behavior. I have the thought that I want to cut myself, and so I cut myself. It is teaching that you can observe an urge, you can observe a thought and just observe it. If you go to an aquarium, you can observe the fishes. You don't have to fish them. You don't have to eat them. [00:18:11] Let the thought float by without. Or, at least have a decision about whether you're going to act on it. Because if you say, I'm having the thought that I am hungry and I haven't eaten for 6 hours, maybe that thought is a useful thought. If I've just had six donuts and I have the thought, I'm hungry, maybe I can say to myself, I'm observing that thought, but I don't have to act on it. [00:18:38] [00:18:39] So it is creating a space between the thoughts and the phenomena of the experience and behavior. This is where this idea of mindfulness came in. For very impulsive people, this idea of being able to slow down and observe their minds at work was very important. [00:18:59]

KEN: [00:19:00] You also mentioned interpersonal effectiveness. [00:19:03]

BLAISE: [00:19:03] So many people who are emotionally highly sensitive have many things like the rest of us that they want. But often the way that they go about those things and go about the requests are disrupted because strong emotions drive ineffectiveness. Then if relationships have been disrupted, then how to repair those relationships. The other idea is that I may have a mind and it tells me that you have certain intentions, but it's also thinking about what might else be going on in that other person's mind that they're acting in the way that they are, without assuming that the thought that I have is the correct thought. [00:20:06]

KEN: [00:20:16] Distress tolerance is another big thing you mentioned. [00:20:18]

BLAISE: [00:20:18] Right. So when people are in a lot of emotional pain, their ability to tolerate distress is compromised. And so, one of the things that happens is that they will often do things that alleviate the distress as rapidly as they can. Maybe dangerous, sexual encounter, maybe self-injury, maybe drug use. Now, those things work really, really quickly to change the emotional environment of the brain. [00:20:53] [00:20:57] So even though they're very effective, they have their own consequences.

Because it takes a while for people to be able to sit with that distress. We teach things like, maybe listening to music or other stuff that many people do when they're in distress, you know, read a book or call a friend, those kinds of things, but make it a much more intentional part of the repertoire that a person has rather than just hoping that things will end. [00:21:49]

KEN: [00:22:17] And of course, emotional regulation is one of the core things. I wanted to ask you a little bit about that. [00:22:22]

BLAISE: [00:22:23] As we said earlier on, really strong emotions can lead to very ineffective behavior and strong emotions can be really painful. If you think about the worst day of your life and when you're really emotionally upset by something that had happened, and you had to live that day over and over and over again, you might think it's not worth it. So you think, Wow, these emotions are so painful. So how do you regulate them? We teach ways to regulate them by, first of all, paying attention to vulnerability factors like physical illness. And we've seen during COVID that people have become more irritable and maybe more depressed. [00:23:15] [00:23:31] And then if you have a mood state that tends to get you to do something that is long term ineffective or long term consequential, that's a school that we call opposite action. So, say I'm depressed and I stay in bed. But what we know is that staying in bed probably keeps you depressed. So opposite action is doing the opposite of what your action urge tells you to do, which is to get up, take a shower, or go for a walk. Now, I know it's difficult, but it's interesting that when people are depressed, [00:24:07] [00:24:10] they don't give up the things that keep them depressed. They give up the things that make them happy. Don't give up the things that make you happy or that make you connected. Give up the things that keep you depressed. Like isolation. Like staying in bed. Like not eating. [00:24:27]

KEN: [00:24:51] So how do you know if your clinician understands the principles of DBT? And at what point do you think you need the full monty of the whole DBT endeavor? [00:25:02]

BLAISE: [00:25:03] I certainly think that if somebody is suicidal or somebody is self-injurious, if somebody is somebody who tends to not show up in therapy, if somebody is, because of their mood states, getting fired or resigning from jobs or not going to school or in and out of relationships. To me, that person is probably somebody who would need the full DBT treatment. If somebody has some problems with this regulation, but, you know, they're able to go to work. They're able to go to school. They're able to maintain their relationships, you know, then

maybe they might be able to use more CBT and other approaches. [00:25:56] [00:26:21] And so the question is, are you as a consumer, Ken Duckworth, looking for a DBT therapist? You know, I say I've done DBT. How do you know that I've done the DBT that somebody else has done? You know, have they have they listened to some YouTube videos by Marsha Lineha? Have they gone to a one-day course, a two-day course? [00:26:42]

KEN: [00:26:43] Did they read a couple of Blaise's books? [00:26:46]

BLAISE: [00:26:46] Exactly. Did they read it and they call themselves a DBT expert? [00:26:49] [00:27:53] So you'd want to ask those kinds of questions, where did you train and how long can you train for? Do you sit on a consultation team? Do you see people with borderline personality disorder? Do you treat suicidal patients, etc.? [00:28:05]

KEN: [00:28:06] I happen to believe that the world would be a better place if all high school students were exposed to the principles of DBT. Do you agree with me? [00:28:15]

BLAISE: [00:28:15] Yeah. And in fact, that's one of the things that I've been recently lobbying for and actually now our hospital has a school consultation service for, and they're trying to introduce DBT into schools. Adolescence is a time where people are questioning their identity, where they have trouble regulating their emotions, where life is confusing. Learning the skills to be able to manage all those things as early on as you can, even beyond before high school. And just start with simple lessons on what emotions are and how to regulate them and how to talk about mental health. We insist on physical wellness. Everybody has PE class. Yes, but we don't have ME class. We don't have mental wellness classes. Yes, a mental exercise class. [00:29:16]

KEN: [00:29:16] Yes. And if you look at all the causes of disability in youth, it's mental health and addiction, right? [00:29:22]

BLAISE: [00:29:23] That's correct. [00:29:23]

KEN: [00:29:24] People are not suffering from diabetes for the most part at age 16. [00:29:28]

BLAISE: Exactly.

KEN: [00:42:30] Blaise, I once had a patient call it "diabolical behavior therapy" because there was so much homework involved. Have you heard other criticisms of DBT? [00:42:39]

BLAISE: [00:42:40] Yeah, one of my patients called it "death by therapy." Some of the criticisms are that, you might as well just hand the patient a manual. It's a manual treatment. If you were to speak to my patients, very few of them would say that we don't have a relationship. it's really a very, very connected treatment. You know, if somebody is learning how to skydive and you say, read the manual jump out of the plane, you have to trust that the person who is teaching you is going to give you good advice. [00:43:18] [00:46:05] A couple other criticisms - that that DBT is a cult, but the thing about cults, often there's secret handshakes and you have to do certain things. DBT is very transparent. And in fact, if you were to say treatments for borderline personality disorder, look at all the studies. DBT swamps all the other types of studies put together-- psychoanalytic studies, nursing, and all of that. And they've put themselves out there to the test and be very, very transparent. There's not, I think, where the cult idea of a came in is that, you know, people admire Lenihan tremendously. But in New England, we admire Tom Brady because he's done great things for the Patriot football team. But just because you admire someone doesn't necessarily make it a cult. And then there's the practice of meditation and mindfulness. Now some people will get into very mystical mindfulness practices, but you don't need any of that to be mindful. And also, one final thing is that DBT is not only for borderline personality disorder. We have seen it be used for substance use disorders, eating disorders, depression and anxiety, post-traumatic stress disorder, and just life, and in schools. [00:47:31]

Ken: Well, this gets back to the ideas of middle school and high school. Skills for living. Blaise, thank you so much for your help in this.

John: [00:28:05] That was Dr. Blaise Aguirre, and he is the author of Borderline Personality Disorder in Adolescence: A Complete Guide to Understanding and Coping When Your Adolescent Has BPD. We're going to take a short break. When we come back, a lived experience expert who has been managing her borderline personality disorder with tremendous help from dialectical behavior therapy. This is The Medical Mind. We'll be right back. [00:28:31][26.5]

[BREAK]

[REJOIN MUSIC]

Ken: [00:28:32] Welcome back. This is The Medical Mind. I'm Dr. Ken Duckworth. In my travels in the National Alliance on Mental Illness, I come across many remarkable people. One of them is Cathleen Payne, a woman who gave a talk some years ago that really helped me better understand what it's like to live with borderline personality disorder and how DBT can change lives. Cathleen has gone on to do many remarkable things and runs a website with strategies and tactics. Tips for relationships when you love somebody with borderline personality disorder. [00:29:06][34.0] Cathleen Payne's website is https://porcupinelove.com/.

[MUSIC BUTTON]

CATHLEEN PAYNE INTERVIEW

CATHLEEN: [00:00:36] My name is Cathleen Payne. [00:00:38] [00:01:18] I live outside of Washington DC, in Arlington. I am a volunteer where I spend a lot of my time helping a nonprofit global organization called National Education Alliance for Borderline Personality Disorder. Because I am a person with the condition of borderline. [00:01:34]

JOHN: [00:01:43] Cathleen, how old were you when you first went to therapy? [00:01:46]

CATHLEEN: [00:01:48] Oh, I went to therapy in college, so I was about 18 or 19. [00:01:53]

JOHN: [00:01:54] Okay. What was going on in your life at that time? [00:01:57]

CATHLEEN: [00:02:08] I had a suicidal incident where I was planning to jump off the stadium where I went to school. And there was a security guard that found me and was so kind to me, talked me through it and said that he wanted to assure that I would get help for my mental health. And he kind of made me promise that I would go to the student health center and ask to see a psychiatrist and a therapist. [00:02:48]

KEN: [00:03:21] But you know, when I interviewed for NAMI's first book, your journey to getting a right diagnosis was quite an important piece of your experience. Could you share a little bit about that? [00:03:31]

CATHLEEN: [00:03:34] Sure. I've probably been to about 30 different therapists. I don't remember the number of psychiatrists, but probably about seven or eight. But over time, I was diagnosed originally with depression and treatment resistant depression. And then when I had my second child and I was in a huge postpartum depression, I was diagnosed with bipolar and prescribed, all along, different medications for those different diagnoses. And nothing really had helped with the rages, the utter, excruciating emotional pain, and a lot of interpersonal conflict that was going on in my life. I was able to function professionally, but in my personal life it was just nothing but chaos, and a rollercoaster of fighting and making up and fighting and getting counseling and going to marriage counseling. And finally, one of our marriage counselors mentioned that I might have borderline. And so my husband started getting on the Internet and exploring what borderline personality disorder involved. And he just kind of said, this is us, this is what we're experiencing. And he ended up going to a family support skills and education network called Family Connections. And I was furious. I was so angry that he was going to be a psychiatrist now and diagnosed me with borderline, which I did not want. [00:05:32]

KEN: [00:05:32] "How could *you* make another diagnosis after I've already had so many that were also wrong?" [00:05:36]

CATHLEEN: [00:05:37] Yes. I mean, I was this intelligent, functioning attorney. For some reason in my mind that equated to I couldn't have another mental health diagnosis, especially borderline. It was such a horrible diagnosis and I was really angry. But when he came home with some skills from that class, like validating my emotions and started to say things like, "Oh, I could tell that it would be really hurtful if you thought I did this because I didn't love you anymore, that would really hurt." And I was like, Oh, I can actually stay in this marriage if he's, you know, he's getting a lot better. [00:06:18]

JOHN: [00:07:05] What was your life like together during that time? [00:07:08]

CATHLEEN: [00:07:09] Well, we had a year of separation in 1996 when we went to marriage counseling, and we were doing it with the goal of trying to reunite. But that wasn't when I was diagnosed with Borderline. So it was several years later when we were actually thinking about getting separated again and we were thinking, we've tried everything. This is going to be the end.

JOHN: [00:07:48] Was it a lot of fighting? Was it a lot of yelling? Was it distancing? What was going on in the marriage? [00:07:53]

CATHLEEN: [00:07:54] there was so much fighting and crying and wishing I were dead. On his on his behalf, I have to say, he was taking a lot of that anger in and didn't have any more room for it. I exhausted him. [00:08:20]

JOHN: [00:08:30] I want to get to this idea of "porcupine love" in talking about your experience with borderline and with your marriage. You've used this term "porcupine love." What does that mean? [00:08:42]

CATHLEEN: [00:08:47] I have to say that with borderline, I feel so much emotional pain when something happens. It's obviously way out of proportion to the circumstances. But when I feel hurt by something very small and I'm like escalating into all my emotional pain and screaming and yelling, "This hurts," I feel like I'm receiving quills from him. But he's also feeling my quills where I am yelling and blaming him and being sarcastic and rolling my eyes and sighing. I mean, constant quills back and forth. "This hurts." And I take it out in my voice. So we both feel the quills of each other, but we also both really love each other. We see wonderful, loving qualities in each other. And it's just trying to find a way to find the loving places, even though we both have had our share of hurtful places. [00:09:56]

KEN: [00:09:57] Cathleen, how many years have you been married? [00:09:59]

CATHLEEN: [00:10:00] 36, almost 37 this August. [00:10:02]

KEN: [00:10:03] Fantastic achievement. And I'm impressed that you had separations in order to problem solve. [00:10:09]

CATHLEEN: [00:10:11] Yes, we felt like there was such an atmosphere in the home and we had young children, that we didn't want it to be like a war zone, [00:10:22] [00:10:28] feeling like that was just so hard for the kids to have to live in. And we didn't know what was going to happen. We were just committing ourselves to trying some marriage counseling so that we could make it into an environment where we could raise our kids. [00:10:43]

JOHN: [00:10:44] So did the borderline diagnosis come from a psychiatrist that you were seeing? [00:10:52]

CATHLEEN: [00:10:52] Actually, my psychiatrist that I went to told me there was no such thing as borderline. When my husband found Family Connections, I went

to my psychiatrist privately whispering, my husband thinks I have borderline. And she said, "There is no such diagnosis. It's something that people have said lies in between other diagnoses." [00:11:19]

JOHN: [00:12:53] How did the diagnosis finally happen? How did that finally get established for you? [00:12:59]

CATHLEEN: [00:13:01] Well, as I said, after my husband took the Family Connections class, where they learned some different skills like validation, I was really curious about learning some different skills. And maybe even if I didn't have borderline, I could still learn some ways to manage all the emotional ups and downs, the emotional pain. Maybe I could find some new interpersonal skills or something that could help my marriage. [00:13:31]

JOHN: [00:17:54] Something about the DBT kept you coming back, though. Can you think of a moment when this treatment really clicked for you? When you thought, okay, I'm on to something here. This is making sense. [00:18:02]

CATHLEEN: [00:18:05] I took DBT three different times. And the first time I was really just trying to survive each day, trying not to be suicidal every day [00:18:17] [00:18:22] And the second time I did learn more about how it all works, like emotion, mind and wise mind and trying to get the space between your emotion and your actions. So, I think I learned every time I took it. The third time I really did just kind of hone in on those actual... there's so many different DBT skills and I think the third time was when I really found the ones that worked for me. I worked really hard on saying, Oh, this really works, or this doesn't speak to me so much. So I think it was just a lot of practice and trial and error. It wasn't like one particular time. [00:19:04]

JOHN: [00:19:13] What were the skills that ended up working for you? [00:19:16]

CATHLEEN: [00:19:19] I found that I had to really work on the stress tolerance skills first. [00:19:38] Like STOP is: stop, observe, take a breath, and pause. Or TIP is like temperature, intense exercise, and I forget what the P is. But I just kind of picked out different things that I had to do when I was totally dysregulated. I found that sometimes journaling where I'm just writing what I want to scream out to the world instead of screaming it, I try to journal it and that helps me until I can stop writing. Like "it hurts. It hurts, it hurts" until it just hurts less. Because I couldn't really get to the other DBT skills of like taking my breath and noticing my feelings and being mindful without judging my feelings or my thoughts. I had to

be at a lower level of intensity in order to get any benefit from some of those mindfulness skills. [00:21:41] When you're highly emotional, you don't really have access to your cortex, your thinking skills. I find that a lot of DBT is your reasoning with yourself. You're trying to think yourself through things. Those are great skills, but they haven't been always what's needed in my marriage to deal with all the hurts on both sides of the relationship, to make it sustainable over time. My husband and I kind of made up our own DBT skills about what we call a repair. Like, after my emotions come down, I need to repair for my screaming or my yelling or my negative words. [00:22:32] [00:22:59] So we came up with the 60-second repair, because a person with borderline, [00:23:03] [00:23:06] if you start listening to a loved one saying, Wow, you really laid into me and your voice was so harsh and disrespectful, don't you want to treat me with respect? At first you're like, I get it. And then you hear more and more of it and you start thinking, Oh my gosh, I'm such a horrible person. Oh, I wish I were dead. So I could only listen to 60 seconds for repair in the beginning [00:23:32]

KEN: [00:23:34] But that's not a DBT skill, per se. You and your husband created that working off of the DBT framework. You create something that works for the two of you, which is pretty brilliant. [00:23:47]

JOHN: [00:23:50] Yeah. What changed you from being a client or a patient working on DBT to being an advocate? [00:23:58]

CATHLEEN: [00:23:59] Oh, I'm still very much a client and a patient. Actually, I was still really working on getting therapy and finding the right care providers. My husband and I were still in the midst of a lot of painful marriage issues, when Dr. Perry Hoffman came up to me and said she needed somebody with the condition on the board of directors for the National Education Alliance for Borderline Personality Disorder. She wondered if I'd be willing to serve and I hesitatingly said, okay, we'll give it a try. And I've been secretary of the board ever since. [00:24:58]

JOHN: [00:36:15] What do you think people should know if they're thinking about trying to get into to dialectical behavior therapy? What do you wish you would have known? What do you think people ought to know? [00:36:27]

CATHLEEN: [00:37:19] I would ask some very pointed questions. I probably would go on some Internet resources that tell you how to interview a therapist before you sign up with them. I think the most important thing to tell people is that emotional pain isn't going to go away if they have a mental health condition and

to just get help because there's no way we're given in life everything we need to know about dealing with our emotions. And I think that's the most important message, is just to get help and to get someone that you think will understand you and what your problems are. [00:38:06]

KEN: [00:38:07] Cathleen, do you have a favorite book or resource that you would recommend? [00:38:11]

CATHLEEN: [00:38:11] I would say *DBT for Dummies*. I go back to that all the time. [00:38:16]

KEN: [00:40:55] Do you want to talk about your porcupine love website? [00:40:58]

CATHLEEN: [00:41:02] I am writing blogs onto a website called https://porcupinelove.com/. My blogs are simply types of skills and knowledge and experience that I and my husband of 36 years and going have developed. I would love to share that knowledge with anyone who feels like they could benefit. But it's mostly for couples where one has emotional dysregulation or borderline.. [00:41:40]

[MUSIC BUTTON]

Ken: [00:43:07] Yeah, it was great to talk to Cathleen and I have such admiration for her and her courage and leadership and helping others who live with borderline personality disorder. Cathleen has a website. She just mentioned it: https://porcupinelove.com/, which has tips and strategies that she has used and found helpful. I also want to mention that Cathleen is one of the 130 people that I interviewed in NAMI's first book, *You Are Not Alone*. Cathleen discusses her relationship, her parenting, and what she's learned from DBT. [00:43:43][36.3]

[THEME MUSIC]

OUTRO & CREDITS:

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