

Personal Perspectives on Bipolar Disorder (The Medical Mind Podcast)

EPISODE 1

This is The Medical Mind, a podcast about innovations in mental health care from the American Psychiatric Association. 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.

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The topic for this episode is bipolar disorder. It is the first of a two-part discussion led by Dr. Ken Duckworth. He leads a deep discussion that offers insights for individuals, family members and mental health professionals. Living with it, loving someone who has it, treating it, the impact of cultural identity, and so much more. Let's dive right in.

Ken Duckworth: Hi, this is Dr. Ken Duckworth, I'm the Chief Medical Officer for the National Alliance on Mental Illness, also known as NAMI. Today's conversation is about learning from the experience of living with, or loving someone who has bipolar disorder. We have three fabulous guests today, Marleyna Illig, who lives with bipolar disorder; Monique Owens, who loves a daughter with bipolar disorder; and Dr. Melvin McInnis, a professor of psychiatry at the University of Michigan, who studies people who live with bipolar disorder.

[00:00:36] This conversation is designed to make a difference for people who have been given a diagnosis of bipolar disorder and to extend their learnings, so that a listener can pick up some developments for their own life.

[00:00:50] So let's start by just saying hello and checking in on how everybody's doing now. So would you just introduce yourself, say how you're doing today, just for starters?

[00:01:05] **Marleyna Illig:** Hi, I'm Marleyna and I am doing very well today.

[00:01:15] **Ken Duckworth:** Monique?

[00:01:22] **Monique Owens:** Hi, I am Monique Owens and I am doing fantastic today. Thank you for asking.

[00:01:31] **Ken Duckworth:** And, Dr. Melvin McInnis.

[00:01:33] **Melvin McInnis:** Good afternoon, I'm doing very well. We are enjoying a very nice day here in Michigan, the sun is shining and so, good things happening today.

[00:01:43] **Ken Duckworth:** Excellent. So, this is a conversation about bipolar disorder and what you all have learned. Marley, I'd like to start with you as you reflect upon your experience. Is there anything you'd like to share about what you've learned?

[00:02:01] **Marley Illig:** The biggest thing I've learned is that there is no way I am ever going to have learned everything. I've become so much more aware that my mind does not work the same as everyone else's, and it's just basically been acceptance of my mental challenges and learning how to not be so hard on myself, but not using it as an excuse to not live my life.

[00:02:39] **Ken Duckworth:** There's an acceptance, a moving ahead. There's a lot of pieces to it. Do you want to develop a little bit more the idea of, you know, what you've accepted that your mind might be a little atypical in some ways?

[00:02:54] **Marley Illig:** I really feel like the past year in itself, since I started extra therapy and really taking care of my self-care and mental health, I've learned that, just because my mind doesn't work the same way as others does not mean that there's anything wrong with me. I feel like a lot of the time I used my situation with bipolar and the self-medication that came with it, as kind of an excuse to not do my best and not really get my life together. I think a lot of the acceptance for me is realizing that I am not crazy. And, I think that's a big thing is realizing, there's not anything wrong with you, it's just that your mind works differently, and that I can still lead a really good life. It's just, you have to work a little harder.

[00:03:52] **Ken Duckworth:** So, you have a very sophisticated take on it, which involves both acceptance, but not self-blame while still moving ahead.

[00:04:00] May I ask how old you are?

[00:04:02] **Marley Illig:** Yes, I will actually be 31 in about three weeks.

[00:04:09] **Ken Duckworth:** What age were you when you started to put these pieces together? Okay, I have this phenomena. I'm not crazy. I have to deal with it and accept it, but also move on.

[00:04:28] **Marley Illig:** That was a year ago. It was age 30. I was diagnosed at age 14 and it's been an ongoing struggle ever since. It wasn't until just about this time last year that I realized, you're not crazy and you're going to need to take care of yourself.

[00:04:45] There's going to be work involved, but it's worth it.

[00:04:49] **Ken Duckworth:** Were you given the diagnosis of bipolar disorder at age 14?

[00:05:04] **Marley Illig:** I was diagnosed at age 14. I've been diagnosed with other things since, but my first diagnosis was at age 14.

[00:05:12] **Ken Duckworth:** Of bipolar disorder? So you think they got it right the first time?

[00:05:17] **Marley Illig:** I think they've gotten it right every time.

[00:05:24] **Ken Duckworth:** Got it, and the journey has been more within you, but it's a lot to take in as you're growing up and developing an identity.

[00:05:35] **Marleya Illig:** Yes, it absolutely is. I self-medicated a lot to not have to deal.

[00:05:45] **Ken Duckworth:** That's a very common response and I wanted to ask if you feel comfortable developing that a little bit. How did you experience the self-medication idea?

[00:05:55] **Marleya Illig:** I actually started binge drinking at around age 17 and eventually I became addicted to opiates for five and a half years. I actually just celebrated seven years clean from drugs on the 23rd of July.

[00:06:15] **Ken Duckworth:** Congratulations.

[00:06:17] **Marleya Illig:** Thank you.

[00:06:18] **Ken Duckworth:** It required a full stop, right? So you have no contact with substances?

[00:06:23] **Marleya Illig:** No, I quit drinking, I quit smoking cigarettes. The only thing I take is, very occasionally my anxiety medication, but other than that, I don't do any self-medication.

[00:06:36] **Ken Duckworth:** Boy, that's quite an achievement.

[00:06:56] **Marleya Illig:** I think that, quitting drugs really forced me to sit with myself because I didn't have what was taking me away from my mind. So, learning how to sit with myself and sit with my emotions and learn how to deal with them on my own was a really big stepping stone in accepting my disorder, and also learning how to handle it.

[00:07:23] **Ken Duckworth:** Did you get support from family or professionals to help you with either the idea of stopping the use of substances or in this kind of advanced acceptance?

[00:07:41] Do you think it was clinicians, family members, church? What were the forces that helped you? What were the supports you had?

[00:07:49] **Marleya Illig:** It was my mom. It was my mom, my grandparents. I did have support from my behavioral health provider, but as supportive as they were with just getting me to the places I needed to be, it was my family that kept me there and kept me doing what I needed to do to stay.

[00:08:12] **Ken Duckworth:** So, were you able to discuss all this with your family? Many families still struggle with shame and prejudice.

[00:08:19] **Marleya Illig:** Oh, I'm so open with my family. I'm really fortunate. But even the last year, as I've gotten more familiar with my mental health disorders, my mom has been learning completely different ways on how to work with me and learning a lot herself about my mental disorders, as I've learned about it.

[00:08:44] So we've been creating a really good dialogue as to how to work together with it.

[00:08:50] **Ken Duckworth:** That's a beautiful story. Was NAMI helpful to you or your family?

[00:08:56] **Marleyna Illig:** Honestly, I feel like NAMI did a big part in saving my life. I was going through a really difficult time, around this point last year. I decided to volunteer with them and them continuing to talk to me, really helped me, by giving me responsibility because going out and sharing my story and talking to the kids in the community and the adults, I think, ended up being really therapeutic for me, and kind of giving me that purpose made me feel like there were still things worth fighting for and worth living for.

[00:09:31] **Ken Duckworth:** That's a beautiful statement and I think that's pretty well backed up by the research literature that giving to others, having a sense of purpose, developing meaning from your experience makes a difference. I want to thank you, Marleyna. I want to ask Monique Owens, as a mother, I'm interested-- you're not Marleyna's mother, I want to make that clear. But Monique, my understanding is that you're a parent of a child with bipolar disorder, and I was interested in your process of understanding this.

[00:10:08] **Monique Owens:** Yes. I am a parent of a person with bipolar disorder. She will be 29 on Sunday and we have been dealing with this behavior since she was about 13, but did not get an official diagnosis until she was 21. By that time, she had gotten herself in trouble with the law and, I was already into NAMI because of my other children. From learning from NAMI, I was able to help her pull her through that process. January of this year was the first time Brandy talked to her about publicly her battle with bipolar and how she processed through that. It was difficult as a parent to watch her go through all of that and feeling helpless that I couldn't change things for her, but I never left her side. There were times with her behavior, we as a family, just wanted to just let it go.

[00:11:19] But, somewhere along the way, when she realized that I wasn't going to give up on her, and even through that process, we were still there to help her through, to talk with her, to show her that she needs to get the help. She actually went to get help. Through that process, even when she was going through the court system, it's still helped her become calm. She came to grips with her illness and while she was in jail, she was talking to the other young ladies in there and helping them through their process too. Right now, her best thing is to come and talk with us. She used to self-medicate. What she did was marijuana. That was her vehicle of choice. But, her main grip was stealing and it's theft that got hurt in jail.

[00:12:13] So, she had learned when she had that moment to sit with herself in jail, was when she came to herself and said, I need to really get help and get out of this. And so, now the family is rallying around her, her siblings rally around her. We all check in on her on a consistent basis. Her boyfriend comes to me and says, I'm not sure what's going on with her today. What do I do? So, we have everybody, even her employers, they help her when she's having a bad moment. We're helping to keep her on track.

[00:12:51] **Ken Duckworth:** I hear a lot of love and a lot of communication. Did you know anything about bipolar disorder before this came into your family's life?

[00:13:02] **Monique Owens:** Not at all. This was completely a blind side to us. I was aware that something was happening, but I did not know what it was called. Far from my mind was it bipolar. I knew that she had been diagnosed with ADHD. But it started changing and I said, that's not ADHD. What is this right here? And so, it was not until I got into NAMI and I started teaching the family to family course, and the basics course, where I started learning a lot more. And through those resources, I was able to give her the help that she needed.

[00:13:46] **Ken Duckworth:** Excellent. NAMI's family to family and NAMI basics courses, both are psychoeducation programs to help people learn more about the conditions that happen very commonly and also, an emphasis on self-care. And, sustaining yourself to be a loving family member.

[00:14:25] Did you take away anything else from those courses?

[00:14:29] **Monique Owens:** I took away, self-care was the number one thing because I was going through physically stress. The stress was landing me in the hospital way too many times. She would disappear for days at a time and then, not knowing where she was and I was always in the worry and anxiety state myself. So much so that, I wound up having to go see a psychiatrist so I could get some help. And then I was on medication just trying to stabilize myself.

[00:15:03] So, NAMI helped me understand that it's okay if you have to get that help, because I have to be able to help myself before I can help her.

[00:15:19] **Monique Owens:** That was the turning point for me. I learned to take care of me and when I did that, I was in a much calmer state to be able to help her. Then the rest of the family started seeing the change in me. And then they started coming on board, like, well, mom's not fussing as much, or mom is not stressed out as much, or this would have taken mom out before, but she seems to be a lot calmer. What are you doing? And I say, Hey, I'm learning. I believe that the education is key because once you know what's going on, you become more empowered in how to handle it. Therefore, the fear is gone and now we can work with the solution.

[00:16:07] **Ken Duckworth:** Was it difficult for your family to take up this topic? Because not every family finds this easy. There can still be a lot of shame and prejudice in our society.

[00:16:20] **Monique Owens:** It was not as difficult as we thought. Because when I got into NAMI, my first night, I realized that there were other families going through the same thing. Which gave me a relief, which gave us a relief that we're not crazy.

[00:16:40] **Monique Owens:** We are not alone. When we realized we were not alone and I talked with the family, say, okay, this is what's happening with her, what can we do to help her? And in turn, my whole family has actually taken the basics course. And some of them are taking the family-to-family course. So getting the education throughout the family helped us be able to help other families.

[00:17:30] **Ken Duckworth:** I wanted to ask you, Monique, about her experience of going to jail. The overuse of the correctional system for people with psychiatric illnesses is a huge

problem in America. But, it sounds like for you it was a moment when your family was able to pull together. Is that accurate, or would you say the consequence of jail had meaning for your daughter? Or how do you think about it?

[00:18:12] **Monique Owens:** For my daughter and her situation, I think that the jail consequence is what was needed for her.

[00:18:23] She did not want to go to the doctors. She didn't have the hospital experience that other people went through. Hers was more on the track of the justice system. It was as if she was making a beeline for that, so I had to learn how that works and learning how that worked help process through the situation where yes, I believe that a lot of people are in that system unnecessarily. That they could go through the medical and get the treatment and so forth. I strongly suggest that people we'll go through the medical process. Do not go through the juvenile justice or the justice system, period. Because there's too many of them there that need to be actually treated, alternatively.

[00:20:24] **Ken Duckworth:** Well, Monique and Marleyna, I want to thank you both. Dr. Melvin McInnis, professor of psychiatry at the University of Michigan.

[00:20:33] Dr. McInnis, you study people who live with bipolar disorder. And one of the things you've been trying to sort is, what helps people do well with this common and very serious condition? I was interested in your thoughts about that as it relates to our two experience experts, who've already spoken.

[00:20:55] **Melvin McInnis:** Well, thank you very much, Dr. Duckworth. And thank you to Marleyna and Monique for being so descriptive and eloquent in describing your experiences. One of the two things that you both highlighted, the importance of, and that was information and education. I was impressed with your comments, Monique, about how really easy it was to go and get information.

[00:21:23] And I was also just impressed with Marleyna's point about the realization of the needs to get the substance abuse under wraps and to get that treated. That really emphasizes the importance of NAMI, both in the context of information and education and in studying what helps people to get well, what keeps them on the road to wellness is precisely information and education. What we're learning in our studies is that the individuals who are able to utilize the information from ever so many different sources, from their abilities to engage their family members in their care, and their abilities to work with their therapists and treatment providers, is really key.

[00:22:15] What we've also learned is that we are students ourselves in the treating community. We're learning from individuals with the illness. We're learning about what it is that keeps them well. And what it is that causes them to have problems. The personalized elements of care are really highlighted here because one of the important things that a care provider can do is really learn what the triggers are for an individual and what the triggers are in the context of their difficult issues. It could be relationships, it could be jobs, it could be any number of things. And also to learn what their strengths are. We want to be able to identify ways to maximize the strengths and ways to minimize the weaknesses.

[00:23:07] **Ken Duckworth:** That's excellent. You mentioned the concept of triggers and I've been very interested in this in the self-knowledge perspective. I wanted to ask you, Marleyna, first, if you've come to identify things that are predictable triggers for you, that are likely to worsen your condition. And on the flip side, what are the pieces that you've identified that are strengths that you can activate, to reduce the risk of a recurrence of an episode?

[00:23:42] **Marleyna Illig:** I don't get triggered by much, but when I do get triggered, it's really, really heavy. I find that what has triggered me the most is my relationship with my mom. We have a great relationship, but when we have fights-- and it can be something really small. But, any situation where I'm feeling like I'm not doing something well enough, it is enough to throw me into this big tail spin.

[00:24:18] The thing that's interesting is it's not every time. I never know. There's really no way to know what to expect, but a lot of the feelings that get triggered for me is feeling like I'm not enough or that I'm not good enough, that I'm defective. That no matter what I do, it's just not sufficient. I think that's always been a big trigger for me, feeling like I'm just not good enough.

[00:25:07] **Ken Duckworth:** Well, it sounds like you've gotten pretty far on that journey, but interpersonal stress is definitely one well known potential risk factor for recurrent episode. Would you agree with that, Dr. McInnis? Interpersonal conflict or distress. Do you want to talk a little bit about the research angle on that?

[00:25:28] **Melvin McInnis:** One of the underlying features of bipolar disorder is an element of reactivity. Reactivity can be in the moment. It's an emotional response and there's a level of activation, the amount of energy that can erupt in an individual, and the valence where the emotional positivity and negativity that the individual has. Individuals with bipolar disorder appear to have just a little bit more reactivity of an unstable mood. That's really the inherent element of bipolar disorder, is this nature of going up and down. So, what we're interested in learning more about is how we can look at the noise in the system, if you will.

[00:26:16] An individual's level of emotional reactivity just as measured by measures that that would reflect how someone's going up and down, for example, and the sound of their speech over the course of their week, or their level of activity. So, the individual would be able to learn how they're doing and what their level of instability or their reactivity is for that week. One would know when one was at a period, or in a period of time, when one was particularly vulnerable to react in a way that would be less than productive. As Marleyna was saying, it's difficult to predict when these things will go off. And so, it would be wonderful to know when one was at a particular risk period for this to happen and could take off a difficult conversation, for example.

[00:27:14] Or, if one was at a period of time where things are just not going so well and it's probably best to not to go into a particular topic, when one is in a particular state. So, it would be very helpful to be able to identify risk phases of instability.

[00:27:37] **Marleya Illig:** I can say that my big risk is when I have a lot of stressors going on. I have a lot of events going on that are outside of my control. For example, I just started a new job at a rehab and I love it. It's good stressor, but it's a stressor because I'm out and I'm not getting the sleep I was before. I'm also working long hours. And even though I absolutely enjoy it and I love it so much, it's a big change in life and it's a lot going on and I'm learning a lot. Even though things are going really well, those stressors are in the back of my mind. That's a situation where something that usually would not upset me in a conversation with my mom, upset me recently because I do have all these other stressors going on.

[00:28:45] **Ken Duckworth:** There's a whole literature on stress management and sleep. I wanted to talk a little bit about sleep, because many people have told me in my clinical practice that if they can maintain a regular sleep schedule, many people find that very protective.

[00:29:03] I wanted to ask if that's been your experience, Marleya.

[00:29:12] **Marleya Illig:** Yes, I've always had issues sleeping, but luckily, I've been a lot better about it. But yeah, when I don't get enough sleep that's, can make things really turbulent. We had a house fire last year and there was a lot of stressors going on and I was staying awake for upwards of like 20 to 30 hours at a time. That was when I really realized like, Oh my goodness, you are, now is when you need to go and you need to get therapy. That's what's really helped me over the course of the year, but it was my poor sleeping habits that were really sending me into a negative mindset, which was the catalyst in me finally getting the therapy.

[00:30:24] **Ken Duckworth:** Well, this is again, speaking to your capacity for self-learning, because identifying the onset of a recurrence of a bipolar episode, whether it's mania or depression, turns out to be really important. Monique, I wanted to ask if your conversations in your family have looked at stress and sleep as you've worked together to support your daughter.

[00:30:48] **Monique Owens:** Absolutely. That has been the focus of a lot of our talks. As they were growing up, I noticed that they were more like insomniac. I had to fight so hard to make sure that they would go to sleep. They were very outgoing when they were children. They're adults now, so they're still outgoing. They always are like the life of the party, so I had to make decisions where no, the company cannot come because this is a day of rest for us. The whole family has to shut down because we were all suffering when someone was not sleeping adequately.

[00:31:34] The older ones had to be quiet so that the younger ones could sleep. The older ones wanted to keep the lights on all night and keep the games going all night, things like that. So, I had to make a decision that no, we have to shut this down. Everybody has to get rest, because when we didn't get the rest, that's when I noticed we fought more with each other.

[00:31:58] **Ken Duckworth:** More conflict, more stress, but also, did that lead to any of the mood episodes?

[00:32:07] **Monique Owens:** I think it did, because there was always something going on. I don't think there was ever a dull moment in our life for the last almost 40 years. I just don't think there was ever a quiet moment. But I noticed that, when the stressors would come, the mood would change very quickly and then it would become aggressive, where she would slam things down or slam doors.

[00:32:37] **Ken Duckworth:** Irritability, hostility. The highs aren't always feeling up, excited, they can also be irritable and hostile.

[00:32:47] **Monique Owens:** Yes, hers were very irritable, hostile. Most of the time. Then there were times when she would be so loving and caring and everyone was like, Oh, this is great, and we would capitalize on that feeling. Where the family would all rally together, we would all go out. We would do things to keep it going, but then there were times where we could see, we are on the depression side, we're on the side where we have to be more caring to her. Giving her more love and assurance that she's fine. She's more than enough. She is great. She's doing well. The ebbs and flows that she was having, the family is feeling the same thing.

[00:33:30] **Ken Duckworth:** The family was almost required to use different strategies for the different phases of the mood condition, would you agree?

[00:33:40] **Monique Owens:** I agree and there were times, because we weren't educated on it, we did not do well with it.

[00:33:49] **Ken Duckworth:** Well, it's important to be very gentle with yourself because very few people have advanced knowledge of this before they find NAMI or a good practitioner, or have a thoughtful general practitioner, family care doctor or minister. You need somebody in your life to help you learn.

[00:34:08] Dr. McInnis, can you comment on sleep regulation and stress management as it relates to bipolar disorder?

[00:34:15] **Melvin McInnis:** Sleep is really just fundamental to humanity and sleep is incredibly important as a marker in bipolar disorder. Very frequently, we see individuals that have bipolar disorder that have even just one or two nights of really disrupted sleep. And that is the beginning of a manic episode. It's incredibly important to keep tabs on sleep. And very often, these things can happen in a very short time period. It can happen over a course of two to three days. The family and the individual are best advised to have a discussion with their care provider and have a strategy at hand to be able to implement very quickly if an individual with bipolar is losing sleep. It could be, like Monique was saying, about making sure everybody, you know, there's rules that get into place.

[00:35:16] But frequently, it's important to have an extra dose of a medication to take, should there be indicators that the sleep is really going south. Often, it's difficult to get in to see the care provider in sufficient time to adjust the medication. It's really important to have a really strong plan in hand. And so far as stress, stress is something that occurs in our life. I think that Marleya really exemplified that by pointing out, yes, she's in a very good position and really exciting new job. But any new life event that's a positive event can cause a bit of

stress. A marriage or getting into a new school or a new job, those are all wonderful things, but they still cause a little bit of stress.

[00:36:02] One of the things that I've talked to my patients about is that when you're headed into a stressful time, make sure you take time. If you can possibly prioritize some personal time just to relax and recover. It's very important. And family members can really give a good impression, or good idea as to how things are going.

[00:37:02] **Ken Duckworth:** Requires a lot of love and trust, though, to be able to accept that from someone.

That's all for this episode of The Medical Mind. Look for the second part of this discussion, led by Dr. Duckworth, in the Medical Mind episode list.

The mission of SMI Adviser is to advance the use of a person-centered approach to care that ensures people who have serious mental illness find the treatment and support they need. Learn more at SMIAdviser.org.