

Personal Perspectives on Early Psychosis (The Medical Mind Podcast)

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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This episode is the second in a two-part discussion about early psychosis. We continue the conversation with Dr. Ken Duckworth right where we left off in episode 1.

Ken Duckworth: This is Dr. Ken Duckworth, Chief Medical Officer of NAMI and we're very fortunate, to be having experts who are part of the transformation of the public health approach to psychosis the idea of staging intervention. We're very fortunate to have Ky Quickbane, who's going to share his experience.

[00:00:25] Ky, I wanted to say thank you for joining this conversation. And I want to also ask you to introduce yourself if you would, please.

[00:00:33] **Ky Quickbane:** Absolutely. My name is Kyren Quickbane I go by Ky. I am 27 years old, originally from Pittsburgh, Pennsylvania. I started experiencing mental health issues in my adolescence and then experienced psychosis for the first time at age 21.

[00:00:55] **Ken Duckworth:** So, Ky, can you tell us a little bit about the experience? What did you notice about it? What was your experience of it? Was it scary? Foreign? Was it not that big of a challenge for you?

[00:01:13] **Ky Quickbane:** it was honestly overwhelming. At first, the initial symptoms that I noticed were just some paranoid thoughts, and then those evolved into full blown delusions. At the worst of it, it felt like I was reliving the same day over and over and over again, just waiting around for things to change. Until I entered a first episode psychosis program, I was just convinced that I was going to continue reliving the same nightmarish day until the end of my days.

[00:01:57] **Ken Duckworth:** Can you tell us a little bit about the progression?

[00:02:10] **Ky Quickbane:** It was very difficult to recognize without the language around psychosis to describe it. Many of my friends and family became concerned because I had become withdrawn. I refused to participate in any sort of large group activities. I overthought most of the things that I said. At one point, it got to a delusion that if I did something with my left hand, I was controlling the past and if I did something with my right

hand, I was controlling the future. So, that is just a sample of the types of things that you start to experience when it first starts to progress. And then, as the delusions sort of stack, the analogy that I use to this day is stacking like pancakes because they're sticky, right? So, one is relatively easy to cut through, but if you have a stack of Oh, say 50, it's going to take some time.

[00:03:12] **Ken Duckworth:** Right. Now for our audience, a delusion is a fixed, false belief where information doesn't alter your thinking. We've all come to conclusions about something, but then we learn new information and we might evolve our thinking or change our minds. So, it sounds like your experience of the handedness, for example, was quite fixed. There was just a belief that you had that you couldn't be talked out of.

[00:03:45] **Ky Quickbane:** Yeah. Precisely.

[00:03:48] **Ken Duckworth:** Let's talk a little bit about how you found coordinated specialty care, how your family worked with you to find it, if they did, and then what your experience was in the program.

[00:04:01] **Ky Quickbane:** I actually got very fortunate to find coordinated specialty care. My mom got a flyer at work from somebody who worked in the mental health system. At that time, we didn't even know what psychosis was. It was still a mystery as to what exactly was going on with me and I was very resistant.

[00:04:23] The first encounter that I had with my treatment team was actually quite challenging for myself. I was brought into a conference room with everybody who would be on the team, including my therapists, my certified peer specialist or CPS, my psychiatrist, the person who ran the actual first episode psychosis program.

[00:04:49] Again, it was that feeling of just being completely overwhelmed. I was desperate for help, but I didn't necessarily think that it was to the point where I needed all of these people involved and partially, the issue with that is my own resistance to getting help.

[00:05:12] That's one thing that I try to share with other peers, people with mental illnesses, as much as I can, and in my line of work and in my personal life is, you know, it takes a lot of courage and strength to admit that you have a problem you barely deal with by yourself. Engaging them in that room, that day was extremely difficult. I was very withdrawn. I didn't want to make eye contact with anybody. I just got very lucky in that I even encountered a first episode psychosis program.

[00:05:52] **Ken Duckworth:** Were you able to articulate to them it might've gone better for you? Had you been interviewed by one or two people? It sounds like the crowd of the team added stress.

[00:06:02] **Ky Quickbane:** Yes. As the treatment team could see, I was experiencing a multitude of symptoms that was affecting my daily life and my demeanor. And so, the leader of the team decided to meet me at a Starbucks several weeks later. Just sitting down with her and her explaining the program a little bit further and saying, take this at your pace. It's

something that is at will. So, at any point, if you decide it's not for you, you can opt out at the program.

[00:06:42] That changed my mind about how I wanted to go about this. I thought to myself, well, why not give it a shot? Things are not getting better. There's a certain possibility for them to get worse. I decided that it would probably be in my best interest to take the steering wheel of my life, so to speak, and make a change and challenge myself to actually participate in what was going on with myself.

[00:07:15] **Ken Duckworth:** The team leader sounds like she really went out of her way to connect with you as an individual, not in the clinical setting. Meet me at Starbucks and let's review it because your initial interaction with a lot of people sounds overwhelming.

[00:07:30] **Ky Quickbane:** I'm still eternally grateful to her kindness in doing that. At that point, the program was relatively in its infancy. They were looking for more participants and they told me, you fit the bill. You're within the age range, you live in the right place. I try to advocate as much as I can now for these programs to be more accessible for anybody who needs them.

[00:08:01] **Ken Duckworth:** Excellent. There's close to 300 programs across America now, but as you note, you were fortunate in that there was this movement to create a team based, strengths-based approach through coordinated specialty care really only in the past decade or so. Once you were engaged in the program, how did you experience it? What was it like for you? What kinds of things did they help you with?

[00:08:31] **Ky Quickbane:** Initially they made it very apparent to me that it was going to be at my own speed, which was something that I really appreciated because at that time, I didn't know very much about mental health at all.

[00:08:43] I decided that one of the first things that I wanted to work on was getting back into the workforce. I had actually just up and left my job because of a psychotic episode that I was having. I just walked out, so I knew that I was still capable of working, but having that tangible goal of like, okay, here's something that I know I'm capable of doing that I need some support to do.

[00:09:23] Another thing that I wanted to work on was getting around the delusions themselves. That was so central to me because my thought process had just been hijacked, so to speak, by the paranoia and the delusions that I was experiencing to the point where I could barely function in a conversation, let alone a work setting. And so, those two things were my initial steps into recovering. The most central part for me though, was my certified peer specialist. He could relate to me in a way that nobody in my life or in my family or friend group could. It's not even necessarily that he has my disorder, which was schizoaffective disorder.

[00:10:17] He suffers from depression. But his ability to say, I see you, what you're feeling is valid, and I believe that you're experiencing these hardships and I want to help you overcome them and empower you to see the light of the power of recovery and the power of taking charge of your own life.

[00:10:43] **Ken Duckworth:** Hmm. And this is something even the best professional couldn't do, unless they also had a lived experience that they were willing to share with you.

[00:10:54] **Ky Quickbane:** Absolutely.

[00:10:56] **Ken Duckworth:** So, it sounds like the program focused on your goals, which was getting back to work and had this supportive peer relationship that really made a big difference.

[00:11:09] Did they involve your family at the program?

[00:11:13] **Ky Quickbane:** Initially they did not, which was at my request. At the time, I'd had a multitude of delusions and paranoia about my own family. And so, I didn't want them involved in my care at all. However, they did have a few meetings that my parents were present for. So, that helped facilitate difficult conversations that I necessarily couldn't have with them one-on-one about like, okay, this is something that you do that increases my stress or how it triggers me. That was absolutely central to my home life and then my ability to communicate with them as a young adult.

[00:12:04] **Ken Duckworth:** So, understanding the patterns of communication that were both triggering and hopefully reassuring was important. They also sound like they followed your pace. We'll bring my family in when I'm ready for that, is that right?

[00:12:26] **Ky Quickbane:** Yes. That was something that if they hadn't done, I probably wouldn't have trusted the program at all, and that sort of integration was something that I greatly appreciated.

[00:12:39] **Ken Duckworth:** So, this program is trusting you to run the process of when your family's engaged and then provided, the conversation with your family, how to support you better.

[00:13:00] What else did this model offer? Because traditional treatment might not be able to pull off most of those things.

[00:13:09] **Ky Quickbane:** The model presented me with a type of therapy that I had not ever heard of before.

[00:13:31] I thought to myself, cognitive behavioral therapy isn't going to work for me because it is trying to reframe my thoughts and how those thoughts evolve from point A to point B. For me, using dialectical behavioral therapy was something that was absolutely central to making my life worthwhile, which is the goal of DBT, right?

[00:14:02] Having a therapist who was well versed in multiple types of therapy was absolutely critical. Having a peer was absolutely critical. At first, me and my peer, his goal was to get me out of the house and to get me away from a living situation that I wasn't necessarily happy with. The goal was to take me to the mall and just walk around and talk about anything other than the things that were stressing me out. I can talk about those things if I wanted to, but he was very, very, wisely redirecting me towards, okay, what's going on in the here and now, what can you control?

[00:14:50] What are the things that you're grateful for? The combination was DBT and having a peer and the medication. We in the mental health world talk about medication as a tool, one tool in the toolbox, right? I got very fortunate again and that I only had to try two medications, two anti-psychotics until I started to see a change.

[00:15:25] I will self-disclose here, because it's no secret to anybody, but I'm on Abilify and Abilify is a mood stabilizer as well as an antipsychotic. So, that combination of having a peer, having a therapy session where I could talk about anything that was on my mind, it's very open. I think a lot of people have misconceptions about what they assume therapy to be, where it's this red couch, where you're being psychoanalyzed. But it wasn't with my therapist. I had the freedom to talk about anything that was on my mind. Whether that be delusional things or things that I was frustrated with.

[00:16:08] At that time, I probably couldn't tell the difference between the delusions and something that was just stressing me out. Having a peer was totally the keystone into a mental health recovery that I'm still on, but I couldn't be more grateful for the things that I learned along the way about myself and about how I think.

[00:16:33] **Ken Duckworth:** Really, you're describing the kind of perfect blend of the recovery model and the traditional service model, because we do know that cognitive behavior therapy and dialectical behavior therapy have an evidence base.

[00:16:49] We also know that medications like Aripiprazole-- I'll use the generic term for the same medicine that you're taking--clearly have an impact on symptoms for most people most of the time. So, the idea is that you got these recovery oriented, peer-driven services and they were connected to a more traditional, but very important set of services that both addressed your experience, your thinking, coping and also medications to help with the actual biological dimension to the psychosis. Sounds like it was more or less optimal treatment.

[00:17:34] **Ky Quickbane:** I feel like I fell into a pot of gold. I didn't notice a change immediately, which is why one of the things that I tell people who are starting their recovery is, you have multiple tools in your toolbox to build out a wellness recovery action plan, or a WRAP. To know the things that stress you out, the things that help. You know, if you're standing in line at the grocery store, it's not like I can go employ my coping skill of going for a hike. But I can practice deep breathing or visualization or put my headphones in or change locations, to help motivate myself to separate myself from the stressors and just focus on the present and the here and now. You're absolutely right. It was the perfect mix of both of the models of treatment.

[00:18:38] **Ken Duckworth:** That you discovered a pot of gold is such a beautiful thing to hear, because so many people have not had this experience with the early years of their beginning journey, with care. Just to be clear, the wellness recovery action plan, or WRAP as it's called, is yet another recovery tool developed by Mary Ellen Copeland and it helps people identify triggers and what works for them. It's a bit of a map for how to go forward. So, it really sounds like this program pulled together virtually every tool in the worlds of recovery and the more traditional models to help you.

[00:19:26] **Ky Quickbane:** Oh, of course. And, as I said, I couldn't be more grateful and inspired by their work with me.

[00:19:34] I can't imagine that there's any roadmap to how to treat somebody who's going through psychosis or schizophrenia or what have you. It seems like over the years, we've just learned more about it as an illness and learned more about it and how it manifests in people's daily lives.

[00:19:52] **Ken Duckworth:** Well, it's a tremendous service that you're discussing this, because our hope in this podcast is that there are people out there who don't know, like you didn't know what psychosis is and don't know of this model, which makes a difference for people. I think it's really wonderful that you're taking time to talk about your experience there. Can you tell us a little bit about your connection to the treatment program now? Are you still actively engaged in this? Is this an episode of care that you had that made a big difference and now you're onto another chapter?

[00:20:39] How do you think about this?

[00:20:41] **Ky Quickbane:** I'd say it's a mix, in that it's now in the background. I would say that my experience was probably very episodic. However, because the duration of the program, I'm essentially aged out of it. I recovered so well, I've done multiple advocacy projects for the program in order to try and move the program forward to lend my voice to something that's so essential to my life. I still am in therapy. I went from seeing my therapist once a week to now seeing her once every month.

[00:21:28] I am on a monthly injection. So, it's very hands-free in terms of medicating myself, because I go meet my nurse and have a conversation with her and get the injection and that's that. And then just routine med checks once a month to make sure that I'm not experiencing any new symptoms. All I can say as a result of it, is that I am always here to lend my voice to these types of programs, because I think you absolutely hit the nail on the head in that there are now 300 programs. At the start of my recovery, I don't think it was anywhere near that. I can only hope that they continue to evolve and continue to reach people who desperately need them. Because I am just one voice, probably of many, who benefited tremendously from a coordinated specialty care program.

[00:22:35] **Ken Duckworth:** That's great. What's the name of the program that you've benefited from?

[00:22:39] **Ky Quickbane:** It's called Engage. It's run by Wesley Family Services in Pittsburgh in Allegheny County and I believe it's open to anybody between the ages of 15 and 26.

[00:22:53] **Ken Duckworth:** Excellent. You described just a terrific recovery pathway. How do you spend your days now?

[00:23:03] **Ky Quickbane:** Oh, that's a loaded question. I feel more fulfilled in my life than I ever have. As an adolescent, I dealt with depression. Into my college years, I dealt with anxiety and I think that mix eventually led me to having a psychotic break. Now that I've put all of the depression and anxiety behind me, it's not like I don't struggle on a day-to-day

basis, from time to time. However, that experience of going through the coordinated specialty care program and having a team of people who believed in me, for myself and for my own willpower.

[00:23:53] Now I spend my days very far, most days, from depression, anxiety or delusion. I'm an avid hiker. I like to spend time in the woods. I listen to a lot of music. I hang out with my girlfriend and my cats. I never thought for myself that I would have made it this far into being able to build more stable, fulfilling relationships.

[00:24:21] Every now and then I'll plug in a video game and not have to worry about things like delusions that I am actually hurting somebody else somewhere far away by playing them. It's just impacted every aspect of my daily life and given me rewarding coping skills that I probably wouldn't have had if I hadn't engaged in a program like mine.

[00:24:53] **Ken Duckworth:** That's great to hear and it also sounds like you're a resource to that program.

[00:25:01] **Ky Quickbane:** I try to be as much as I can. Advocacy work is something that I'm very passionate about. As an adolescent and a teenager, I always thought that I would struggle with my mental health. I never saw positive things for myself. I've now completed a certified peer specialist training. I'm about to start as a mobile position in the place that I moved to recently. I'm just very excited for the future of myself and the future of mental health as an entity.

[00:25:52] **Ken Duckworth:** That's great. Giving back is really a big piece of a lot of people's recovery. Becoming a peer leader, you can help a lot of people.

[00:26:04] **Ky Quickbane:** Just sharing your lived experience and saying, hey, I've been there, I know what you're going through. I might not necessarily know the specifics of it. But as humans, we all struggle and suffer sort of part of the human condition, but that doesn't mean you have to suffer alone, and you have to suffer silently.

[00:26:24] **Ken Duckworth:** You are not alone. We can help each other through these things. It sounds like your experience with coordinated specialty care is going to have you become a leader in supporting others. The peer leadership roles are still evolving in our society. They are incredibly important because, as you said, the key to your recovery was someone who had walked in these shoes. Not these exact shoes, but that they understood what it was like to have a mental health vulnerability, and they were happy to share with you.

[00:27:04] **Ky Quickbane:** Absolutely. I think it takes a lot of power and courage. But at the same time, vulnerability is true power. You can't get things that you've experienced without being willing to face them.

[00:27:17] **Ken Duckworth:** Ky, one of the questions I ask everybody is a little bit about how your cultural identity, however you define that, has impacted your experience or your family's experience in any way.

[00:27:34] **Ky Quickbane:** Well, that's an interesting question, actually. For me personally, I am a person who does not fit the gender normative of society necessarily, because I actually am a trans male. I knew that I was living in the wrong body, so to speak, for most of my adolescence. Until I have language to speak about it, until I had role models who sort of pioneered the way ahead of me, and my peer who could relate to me by just saying, Hey, I see you and your identity is totally valid. That wasn't something that I got from anywhere else. It took me a lot of self-discovery and self-evaluation to figure out, am I having an identity crisis? Is it something that is my mental health? Is there anybody else like me out there?

[00:28:40] My cultural identity was, I think, very complex in that there was sort of the chicken or the egg question, you know? Am I psychotic because I'm trans or am I trans because I'm psychotic? Having the language to speak about these things and now realize that my mental health was affected by me not fitting a specific mold that was expected of me, has transformed my life and in every way. I could not be more grateful to have figured that out. Through the help of other people and through the willingness of human beings to reach out to another human being and say, I may not know your experience, I may not know anything about you, but I see your identity as a man valid and true. That was so central to my understanding of my mental health recovery, and myself as a person.

[00:29:39] **Ken Duckworth:** How did the coordinated specialty care work with you on that particular challenge? Or was that not an active part of your experience at that time?

[00:29:51] **Ky Quickbane:** Oh, it was absolutely an active part. That's what I mean by saying that this coordinated specialty care was able to integrate me into my family as somebody, you know, who had always been the black sheep.

[00:30:05] I had had dreams since I was 11 or 12 of being just a man. Until I had people in my corner, validating me and saying, your identity is not something that is questionable, it's something that you've known about yourself since the beginning of your understanding of yourself as an individual. And, having their support and their understanding as well as them expressing to me that it was okay for me to exist as who I was, was very liberating. That's the only word that I can think of about it. Because until I had people who said, you're not necessarily an outlier, there are other people out there like you, you just need to seek them out and recognize that there's challenges that are going to be ahead. But you are not in any way all by yourself in this.

[00:31:22] **Ken Duckworth:** Great message. Just a great message. Ky, one of the questions I've been asking on these podcasts is if you were a young person beginning to wonder if you were having a psychosis experience, what advice do you have for that person?

[00:31:41] **Ky Quickbane:** My advice would be to accept help that is readily available. I was fortunate enough that I didn't have to seek it, it just sort of found me. But it is absolutely central to recovery to allow other people to come in to not necessarily invade your life as I once thought was happening to me, but to help facilitate the journey of self-discovery and the journey of self-validation that I had been on for years. I didn't know there's no roadmap to understanding certain mental illnesses. And there certainly isn't a roadmap to an identity

like mine, but having people there to say, your experience is valid and what you've always known about yourself is true.

[00:32:48] It's okay to be different and not necessarily follow a prescribed path or a mold that has been around you. Other than that, you know, it's going to be challenging. It's not something that's done overnight. But the work that comes out of a mental health recovery, And the people out there who were able to help facilitate a mental health recovery are amazing.

[00:33:21] I didn't know any resources when I started my mental health experience, but now that I am a peer and that I know the ins and outs of the mental health system, I am just completely shocked at just how much is available. Whether it be a warm line, whether it be a treatment team through the coordinated specialty care, whether it be writing a WRAP plan, all of these things are just tools that can help you build a life worth living around yourself.

[00:33:55] **Ken Duckworth:** Excellent. That's a great answer. This has been a remarkable conversation and I can't thank you enough for your generosity, both in the time and in sharing your experience. You're going to help a lot of people. I just want to thank you again.

That's all for this episode of The Medical Mind. Look for the first 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.