



Mitul Desai: That same type of literacy that we have for physical health, we need for mental health and that should be taught as early as possible because we all have minds and our minds need care.

Lily Cornell Silver: Absolutely

[music]

Lily: I'm Lily Cornell Silver and welcome to Mind Wide Open, my mental health-focused interview series. Today, I am talking to mental health advocate Mitul Desai. Mitul worked many years in a corporate setting and is now an entrepreneur in workplace well being, and in the mental health space. He also is a board member of the New York City chapter of The National Alliance on Mental Illness. Mitul today is going to share his experiences with his own mental health, his experiences growing up with a brother that has schizophrenia, and what it looks like to be a mental health advocate today, and how you can get involved. Thank you so much for joining and I hope you enjoy. Thank you so much for being here Mitul, it's so lovely to have you.

Mitul: Yes, thank you for the opportunity. I'm excited to do this.

Lily: I would love to get started just by talking about, you worked, or do work primarily in the corporate world. Hearing from you how your mental health journey started even though it wasn't necessarily your main career path.

Mitul: Yes, thank you for asking. The journey that brought me to where I am now, where I'm **sort of** much more involved started really with my brother, my younger brother whose name is Amit was diagnosed with schizophrenia about 20 years ago. Obviously, it has transformed him in very fundamental ways and what he's had to deal with. I cannot even imagine. He has superhuman strength and superhuman grace. I honestly learned from and inspired by him in ways that amaze me all the time, but it also shatters families. I think it's only now, to be honest with you, 20 years later, after a journey like this full of pain and anger and frustration at the system, that we are now able to stop and start to pick up those shattered pieces and say, "Okay, maybe we can talk about this openly amongst ourselves, and maybe there is even opportunities to improve care for my brother."

Now I finally have the emotional capacity to actually think beyond myself and my family and think about how I can help others. But it was a really, really long journey. We had no idea when that diagnosis came, the journey that we would take. No idea. In the beginning, there was a lot of denial. I myself didn't necessarily accept the diagnosis and then even once you accept it, you don't fully appreciate what it is. Every disease is terrible obviously, but I really think schizophrenia is a disease from hell.

Lily: What did a day in the life look like for your brother and for you and your family interacting with him?



Mitul: Thank you for letting me share that. For a long time these really difficult-- Actually, these were conversations I didn't even have because of massive stigma. You think about stigma towards anxiety and depression, for schizophrenia it's 10X

Lily: Totally, yes.

Mitul: Honestly, I couldn't talk about it for the longest time. Only my serious girlfriends knew about it. Everyone else did not know. No one at work, none of my friends, no one knew because I wasn't probably ready to talk about it, to be honest with you. In those moments when you are not ready and you yourself-- I mean, they say that immediate family members of people with serious mental illnesses effectively have PTSD. I'm a PTSD survivor. When you are in that moment of trauma, or that extended period of trauma and you don't have anyone to talk to, and you don't want to talk about it, it's literally like you are pushing down on the lid on top of a pot that's about to explode. That's how I felt looking back.

I thought, at the time, that I was being cool. My brother with schizophrenia was over here on the side and I would deal with it when I had to deal with it, but the rest of the time I was fine. I was going to work and going to school, but I wasn't fine.

[crosstalk]

Lily: Right, just compartmentalizing a little bit.

Mitul: Yes. It impacted my relationships, it impacted me at work. My brother, of course, was impacted the most. There's something called a psychotic break, and it often happens in your late teens or early 20s. For my brother, he went away to college and he came back that summer, and he was a different person. He was angrier, he was staying up sometimes all night, he was drinking more, he was smoking more. At the time, we didn't-- Again, to the point of stigma, there's societal stigma, but then there's even individual stigma. We didn't know, we couldn't diagnose him. We had no idea. We just thought he was just having a tough time at college. We let him go back first semester sophomore year, and in retrospect that that was a mistake because he was on the verge of that psychotic break.

I think when he went back as a sophomore is when it actually happened and he came back and the symptoms were even worse. We could hear him laughing in his room at nothing in particular. He would swat at things in the air that were not there and those were his auditory hallucinations and his visual hallucinations that were starting. He became a lot more irritable, and then we realized we had to seek help and that's when he got the diagnosis. But as I said, this disease is so evil, that one of the symptoms of the disease is that the person thinks they are fine. When you think you are fine, you don't want to take medication. We spent so many years, and not his fault, that's just a symptom, where he didn't want to take medication.

That's a battle in and of itself. Eventually, he's stable, always takes his medication. He's actually starting to draw again. He was an artist, self-taught artist, self-taught drummer, amazingly talented. The medications have massive side effects, really bad



side effects. In some ways, I don't blame him for not wanting to take it sometimes. But yes, there were some things that I would not wish on any person or family. When I see-- There is about 20% of people who are homeless have serious mental illnesses. It's probably higher, actually. Honestly, it's about 25.

Lily: Yes, I was going to say I'm honestly surprised at that number. Maybe it would be higher.

[crosstalk]

Mitul: Yes. Whenever I see a homeless person on a subway or a street who's talking to themselves or acting, I can immediately-- You can just tell, they probably have schizophrenia. Some folks who don't know, and most folks don't know, probably maybe are scared and walk away. It's like instantaneous feel this emotional pit into my stomach that it's like, "That could have been my brother. If just two or three things were different. That could have easily have been my brother." The thing that for the longest time I saw as a source of pain, as something I had to hide, and where I felt sorry honestly for myself ridiculously. When you are young and you are just like, "Why did this have to happen?" Is now the thing that inspires me and I see as inspiration for me to do, probably most of my work going forward.

My brother, some of the things that he experienced are, again, as I said about a homeless person, there's also the criminalization of mental illness. Unfortunately, when there are emergencies for anyone, but for someone with serious mental illness, especially when they are living still with their families, there's emergencies that arise and the family doesn't know what to do and they call the police. The police show up, and the police aren't always trained. Some districts and precincts are trained, but oftentimes they are not. By the way, even if you are trained, that's not your main job. I don't think we should ask the police to do that. They show up and they put the person in jail because that's how they are trained, and by the way, sometimes that person is acting erratically. Actually, most of the state jails and prisons have more serious mental illness patients than the largest psychiatric hospital.

Lily: Wow. Oh, God. Absolutely. Yes.

Mitul: This is the decision that we have made as a society. That we are going to let them live on the streets, we are going to put them into jails and prisons, and we are going to give them medication that maybe works, but has massive side effects. What it does to your mind, and your body, and your spirit, it's violent what it does. What makes it worse, is that our mental healthcare system is sub-optimal, shall we say, or medieval.

Frankly.

If you were to travel back in time, just go to like a treatment center for folks with serious mental illness, or go to a residential facility for folks with serious mental illness. You'll feel like you are literally in 1520, not 2020, given how poor our

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outcomes are, given how the medications have so many side effects, given how health-- the insurance system still needs to catch up. Now, there are pockets of really good care for folks with serious mental illness, but for the most part, it's challenging. It's challenging, right?

Lily: Those aren't necessarily very accessible.

Mitul: Exactly. There's what they call concierge care providers, which is basically super high-end care, which is really good. I know some of those folks who run some of those services. It's really good, but it approaches \$10,000, \$15,000 \$20,000 a month. That's not accessible to everyone. Then there are other more non-profit approaches, like Fountain House, which is an organization I work with, who offer it-- It's effectively free of charge, but their capacity is limited. We're working very hard to expand it including virtually, but their capacity is limited and then they're also working with the system. In some ways, and a lot of experts say this too, it's like trying to change the system, especially for serious mental illness, will take too long or perhaps never even happen, so why don't we create an alternate system and have them follow us?

Lily: Right. Completely.

Mitul: What that alternate system is about, is about things like community-based care and peer-based support, which I'm sure you know about. That's important across all actually mental illnesses, even anxiety or depression, because there's a massive shortage of providers. I think the stat is like 60% of counties in the United States do not have a psychiatrist.

Lily: Wow.

Mitul: Yes. In fact, actually, we're increasing awareness and COVID is increasing demand, but then on the other side, the supply of therapists is not **really** there. Obviously, we need more therapists and psychiatrists, but I also think that you don't need an MD, or a Ph.D., or even a Master's degree to just be caring and just listen to someone. If I think back to me in college and high school, I just needed someone who would listen to me, and who had some basic understanding of the problem. They didn't need to have some fancy degree. Even conversations like this were therapeutic.

Lily: Definitely, and I think in order to get there-- I'm such a huge proponent of implementing mental health curriculum, or emotional intelligence curriculum in schools from like kindergarten so that we are able to grow up having these conversations and not having to wait, as you said your experience in high school, until you're older and looking back and realizing, "Oh, that was my experience, and it could have been different had I had the vocabulary, had I had peer support, had I known what was going on, had other people known what was going on."

Mitul: So important. A lot of folks say stigma is like the biggest unlock. If we get rid of stigma, then everything will follow. There'll be more funding, there'll be better



policies, there'll be all that, which I agree with to a certain level. But the next thing beyond stigma is mental health literacy, which is what you're talking about.

Lily: Exactly.

Mitul: The same way most people know what's good for your heart in terms of eating healthy and exercising, and most people know like if you hurt your ankle, this is what you do, rest, ice, compression, elevation, that same type of literacy that we have for physical health we need for mental health. That should be taught as early as possible, because we all have minds, and our minds need care.

Lily: Yes, that's such a beautiful way to put it. That literacy and that ending the stigma go hand-in-hand, definitely.

Mitul: Those are all decisions. They may be as a result of inaction, but even inaction is a decision and a choice that we're making as a society. You saw the unfortunate incident in Rochester, that man who was suffocated on the street. That happened because his brother didn't know what to do, and in his defense, and he called the police because he's like, "My brother has this serious mental illness, he's acting erratically, I don't know what to do." Many people do that, and the police showed up and that's what happened.

Lily: I'd really appreciate you and you speak to that, because I'm a huge proponent of some of that like police funding at least being reallocated to community resources, but especially towards mental health care because I completely agree that it's asking too much for that to be another task of the police force, and so much of the time they're not trained in it. I see it in Seattle all the time. There's a massive homeless crisis in Seattle and it's very evident that many of them are struggling with mental illness, and they get arrested or they get brutalized by the police, and it only serves to exacerbate the issue. Talking about that structural and societal issue in terms of how mental health is taken care of is so important. Such a huge part of the conversation that I think gets left out a lot of the time, because that's-- as you said, yes.

Mitul: Absolutely. It's a really important issue, and I think this is one where I think this should be a pretty broad agreement. The police don't want to do it, and we don't want the police to do it. It doesn't make **sense**. It doesn't make sense for them. My brother had to spend a night in jail because there was-- This is early on. He was acting really erratically, I wasn't home. Again, just like the brother of the man in Rochester, my parents called the police because they didn't know who else to call. There is no one else to call, and they put him in jail and he spent a night in jail.

Lily: How did that affect his mental health?

Mitul: We didn't really talk about it after he got out, and still haven't talked about it. There are communities that are doing it differently. There's a concept of like either a crisis intervention team, or there's the famous example in Oregon it's called Cahoots. Basically, it's for all non-emergency mental illness calls. Instead of a police, it's a



medic, so like a nurse or an EMT, and like a social worker or a peer specialist type person. That overwhelming majority of the time is what you need. That doesn't result in imprisonment. It doesn't result in a shooting. It doesn't result in any of that stuff.

The easiest thing to do is to get them on medication. Honestly, that's a very small part of the solution, but that's the easiest thing to do. The far more difficult thing again is earlier identification and intervention and then finding non-medical support, whether it's peer-based support, community-based support, a good therapist, a good residential facility. My brother has probably been in 15 different residential facilities across up and down the East coast, till we now found him a place where he has been for a while. Thank God. Difficult times, but we're okay now.

Lily: Tell me a little bit about your experiences with mental health in the corporate world. Have you had personal experiences in that vein?

Mitul: When I left my last corporate gig to do what I'm doing now, which is a bunch of everything in the mental health space, I made a point to tell people why I was leaving, to work on mental health.

Lily: To work on your own mental health or to work on, [crosstalk]?

Mitul: To work in the mental health space. Yes, maybe it was also to work on mine.

[laughter]

Mitul: When you work on your passion, you're definitely happier, so yes, it was my own mental health too. Some of the responses that I got were pretty amazing. People opened up to me about their own experiences in a way that they never had even hinted at.

Lily: Wow.

Mitul: Because just like you in your vulnerability are giving permission for other people to open up, I in my very small way talking about my brother and what I'm going to work on, I gave permission to people around me to open up. These are things I didn't know. I worked with these people for extended periods of time and had no idea that they had anxiety, or that they had a loved one who maybe had suicidal ideation. The things that people told me were amazing. Companies are starting to slowly talk about it. Do you think about the place where a lot of us spend most of our time outside of home, is like-- Well, now even you're doing work at home, but you know what I mean.

Lily: In the office, totally.

Mitul: Yes, in the office. So, it's not like mental health doesn't exist in the office. Companies are microcosms of society, so the same statistics that apply the society apply to companies. Companies are realizing that, and they are improving their benefits plans, they're improving their mental health benefits. The smartest ones and



the most effective ones are also changing the culture. Because you can have the most amazing benefits on the books, but if the culture of the place is not one where employees feel empowered to talk about mental health and to tell their manager like, "Hey, I need a couple of days off," or to the HR person, if the culture doesn't allow that, those benefits are not going to get used.

Lily: What is the work that you're doing now since you've left the corporate space?

Mitul: It's really great. I was thinking about this the other day. It was like, "I really want to go to sleep so I can get up tomorrow and keep working on this." I couldn't wait to go to sleep.

Lily: [laughs] Which is the best feeling ever. That's when you know you found the right thing totally.

Mitul: Exactly, yes. You know what I'm talking about. I serve on a couple of boards, so I'm on the board of the New York City chapter of NAMI, which is the country's largest grassroots mental health organization. I'm on the board of a graduate school of Public Health. They have an accelerator around innovation in that space. I also do some angel investing in mental health tech startups, because I love, love that, and all the activity in that space.

Most of my time is as helping run digital innovation for an organization called Fountain House, which I alluded to earlier, which is this incredible 70-year-old organization that focuses on people with serious mental illness and had this genius insight, which to people like me and you doesn't sound like a genius insight, because it's like everyone should be this way. But their genius insight was that people with serious mental illness also deserve to be treated with dignity, and should be given a purpose in life and should have a need to be needed and should also have jobs and should also go to school and should also do all the things that you and I do and want to do. Actually, that should be the primary thing, not the medication. It's almost like, if your needs aren't being met, and your goals aren't being met, the other stuff isn't going to really be fixed.

Lily: The medication is not going to really be effective.

Mitul: That concept, I think, is going to be to the point about innovation and startups. That is where we're going to crack the code on really giving more support and more affordable access to a lot more people where we can either in-person or virtually have a bunch of Lilys who just have a big heart and an empathetic ear and talk to people and get people to open up. You realize you come away from those conversations when you realize you're not alone, and the conversation itself is therapeutic, and you maybe even learn something. We need to change policies, we need to change funding, all that stuff, but ultimately, we need to change mindsets. Who is best at changing mindsets? Artists.

Lily: Wow. Beautiful.



Mitul: I say artists broadly speaking of our definition. You are doing this as an art form. Creating music is an art form, painting is an art form. If you look throughout history, all the big social movements, artists were involved because at a certain point language and white papers and policy papers and speeches, that only does so much. You need to move people's hearts and minds.

Lily: A lot of the time, that's what lasts throughout history, is that the art stays as relevant as the movement itself.

Mitul: Art to me is like a superpower. It's therapeutic. Like my self-care routine, I wish I could say I'd every morning I do 45 minutes of meditation, and then I drink chamomile tea, and then I take bee pollen. I don't do any of that stuff. I exercise because I need to, my body, I try to get sleep, but then music, music for me, has the quickest impact in terms of making me feel better because it speaks to you in a way that words can't.

Lily: Right. What is bringing you hope right now?

Mitul: The fact that these public conversations are happening is so, so important. None of this existed just even 10 years ago. It's across every industry. It's like even the NBA now, every team has a mental health counselor. Kevin Love talks about this.

Lily: I was just about to say [crosstalk] [laughs] I love that guy.

Mitul: The thing, it's not just that well-known people are talking about it. They're talking about it in very sophisticated ways. It's not just like, "Oh, I have depression and it's fine to talk about it." No, no, no. They know the policy, they know what needs to change. They know how to support it. So, the public conversation is becoming sophisticated. The media coverage is becoming much better that for the longest time if you just look at serious mental illness, and whenever there happened to be violence committed by someone with serious mental illness, they would lump violence and serious mental illness in the same bucket. **And then we'd** think that everyone with schizophrenia is violent.

That's changed. Media coverage is much more intelligent. Policies are changing. In COVID alone, there have been policy changes that make teletherapy way easier to do and to get reimbursement for. The national basic research is improving. The National Institute of Mental Health came out and basically acknowledged that there's still way more that they don't know than they do know about the brain, and the brain is complicated. It's not an easy job, but they're going to increase their basic research in brain science. Also huge.

There's a realization also in this public conversation that medication isn't everything and that you need more holistic approaches, the emphasis on social determinants of health, this concept that your zip code is more important than your genetic code. Housing insecurity, job insecurity, food insecurity, transportation insecurity, all the things--



Lily: Affordable healthcare.

Mitul: Exactly. If one of those things are insecure, trust me, your mental health is not going to be that great, and if you already have a condition, it's going to be exacerbated. This concept of social determinants of health, and not just as this theoretical concept in a paper sitting in some dusty library, it's like insurance companies are like, "Okay, now we get that, and we will actually reimburse you if you take a community-based approach and lower costs." Incentives are shifting.

Then the innovation entrepreneurship piece, which is so close to my heart, lots of really smart, hungry, tech-savvy people who understand that technology is definitely not a silver bullet, but it can accelerate things and taking this startup innovative mindset to this complex problem can lead to new solutions. When that's backed up by the energy and the creativity of young folks, man, just get out of the way because it's going to be beautiful.

Lily: [laughs] I love that. Thank you. Thank you so much for being here, Mitul. It's been so amazing to get to talk to you. I'm so glad we could connect, and thank you for all of your insight. It's been so awesome.

Mitul: This has been great. Thank you. Thank you so much.

[music]

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