

### NAMI Ask the Expert: "I Am Not Sick, I Don't Need Help!" How to Help Someone with Mental Illness Accept Treatment

Featuring Xavier Amador, Ph.D. February 15, 2024

#### **Katie Harris** (<u>00:00:00</u>):

Thank you again for joining, and I will hand it over to NAMI's Chief Medical Officer, Dr. Ken Duckworth.

#### Ken Duckworth, MD (<u>00:00:06</u>):

Hello, everybody. Thank you, Katie, and thank you for all the work that you and your team do. We want to mention, NAMI has a helpline. If you get activated or distressed, there are 150 volunteers at this phone number, at this email address for you to contact. That has come up on occasion, 'cause when you talk about complicated and difficult things, it can be provocative at times. Next slide, please. Our guest today is an old friend of NAMI and the person I consider doing the best work on one of the most important topics in the entire field, and that's how to really work creatively building relationships with people who do not appreciate they are ill. My dad had bipolar disorder, and I saw this all firsthand that he would communicate with a microwave oven when he was psychotic and use it to heat up his coffee just six months later when he was better.

#### (<u>00:01:06</u>):

This was the reason I became a psychiatrist. So I've been following Dr. Amador's work really my whole career, and I'm so grateful for what he has accomplished in terms of helping families really understand the problem and taking creative and relationship-focused approach. So he's a clinical psychologist and is the president of the LEAP Institute. He has many papers and accolades. For today, I'm just going to say how grateful I am for the work you do, Dr. Amador, and for donating your time to NAMI this afternoon. I'm going to take your questions at the other end. Because we have close to 3000 people on this Zoom call, I won't be able to attend to your story in your family. Rather, I'll try to take big themes and get the good doctor to help us and he will make it easy for you to work with him or find him at the end. So thank you, Dr. Amador. Take it away.

#### **Xavier Amador, Ph.D.** (00:02:06):

Thank you, Ken. It's a pleasure to be here, and I liked your emphasis on an old friend because I've known Dr. Duckworth since I think we worked together back in 2001, so it's a special pleasure to be here. NAMI is my second family. I've been a NAMI member for about 35 years. So with that, I want to tell you just briefly about LEAP Institute and how you can contact me when this is over. We provide education about anosognosia and then also about how to use our relationships to engage people in treatment who want no part of what we're offering them. That's the program called LEAP, Listen-Empathize-Agree-Partner. It's an evidence-based program. I'm going to be just describing it briefly towards the end of our time together. We offer courses and trainer certifications. We train trainers as well. leapinstitute.org, I'm going to show you that URL again at the end. Why am I doing that? Couple of reasons. You can contact me through the contact sheet there. I will get back to you.



#### Xavier Amador, Ph.D. (00:03:09):

If we get way too many questions, we'll do our best to figure out a way to respond to most, if not all questions. There's other ways to connect with me and meet with me and come and do a LEAP training or organize one in your community. But let's start where I started. Dr. Duckworth was mentioning his dad. Well, I started this with my brother. This is a picture of my brother Henry and me. Henry's looking in the window of the car. I'm the little guy with his hands on the steering wheel. That picture of two brothers happy to be with each other is really noteworthy because when that picture was taken, we had just immigrated from Cuba. We were refugees. Our father had been killed in the revolution. My mother was alone with four kids, me being the youngest, and she had her hands full, working full-time and it was just a very scary time for our family. My brother was a rock. He listened to me.

#### (<u>00:04:16</u>):

He taught me how to throw baseball, how to ride a bicycle. He was much more than a brother. He was almost a father figure, but he was also a best friend. So fast-forward in your mind's eye, in your imagination, 20 years after this picture was taken that you're looking at, and Henry was living in Arizona with my mom and our stepfather. She remarried a wonderful guy who we called dad, and I was in New York. I was in college, a senior in college at one of the SUNY schools. I get a phone call from Henry in Arizona living with my mom and stepdad. I said, "Hello" and he said, "Come home quick. I killed dad," and he hung up. Now, I didn't for a moment think he'd actually hurt our father, much less killed him, so I got him back on the phone. It took me a while to reach him and what became immediately apparent as he was talking to me is that he was having a psychotic episode. He was hallucinating. He was delusional.

#### (<u>00:05:17</u>):

He believed that his playing the guitar had transmitted music into our stepfather's brain while he was jogging, causing him the trip and fall, and that's how he died. So that's why he was saying he killed our father. He didn't. It was a delusion. He was guilt ridden. He was suicidal because of his guilt, all based on delusions. He was hearing the voice of the devil. Anyway, I flew to Arizona. I flew home. I'll never forget this, being in the living room with my siblings. Our blended family was huge. There's nine kids altogether, and Henry's in his room, like I said, guilt-ridden, depressed, and I'm in the living room with my seven siblings. They all pointed at me one after the other and said, "You go help Henry. You're the psychologist," which was ridiculous. I was 21 years old. I was a senior in college. I wasn't a psychologist. I think the reason they drafted me, they selected me, was because of this picture, what it represents.

#### (<u>00:06:13</u>):

We were very close to each other, and we really trusted each other, and this is a really important aspect of our relationship. There was a lot of trust. So I went and I talked to Henry, and I said, "Look, you're hearing voices. You think you killed dad. Obviously, you didn't kill dad. It's a wild idea that guitar music..." That's the first time anyone ever said to me, "I'm not sick. I don't need help." I bet a lot of you, if you have this circumstance in your homes, have heard the next thing he said to me, he said, "You're the crazy one, not me." I had never used the word crazy, but he felt that I was accusing him of that. It took me a week to get him in the hospital. I tried to convince him. I tried to educate him. I asked him to do it as a personal favor. None of that worked. Like so many of us, I had to call a crisis team, the police, actually back then, this is 1981.



#### Xavier Amador, Ph.D. (00:07:07):

The officers were fantastic. I met them out front, and I explained my brother wasn't well. He wasn't violent, anything like that. He goes to the hospital, he gets an antipsychotic medication, and I was just shocked as to how well he did. He really responded well to it. The hallucinations disappeared. The delusions disappeared almost entirely. After a month, this is back in the '80s, we had a month-long hospitalization, very stable, doing well. We're at a meeting with his psychiatrist and his social worker, and Henry's told he has schizophrenia and the medication he's taking he had to stay on it for the rest of his life. He said he understood and he agreed. We got home, mom made dinner. Henry goes back to his room afterwards. I'm doing the dishes, and I go to throw something in the trash bin under the kitchen sink, and what do you think I found? I bet you know. I found that bottle of medication that I thought was a lifesaver.

#### (<u>00:08:06</u>):

So I fished it out of the garbage, and I was pretty frustrated, I'll be honest. I knocked on his door, and I brandished the bottle. I said, "What's going on? You said you knew that you needed to take this." He said, "Well, that was then. It's better now." I was like, "Henry, that was four hours ago. Come on." That started a seven-year period where our relationship looked like this picture: Henry running away from me, running away from doctors like Dr. Kenworth and others who wanted to help him and also his life went to hell in a hand basket. He was hospitalized oftentimes up to four times a year, mostly involuntarily. He wasn't able to work. He didn't go to college anymore. He dropped out, lost his friends, lost his girlfriend, was homeless for a while, and we're talking close to 30 hospitalizations over a seven-year period. He was really, really ill. No amount of trying to argue with him or convince him, convinced him that he had a serious mental health condition and needed treatment.

#### (00:09:12):

So I was becoming a psychologist during those seven years, and I was on my internship year. I was working on a inpatient unit, and I had this patient, this woman just like my brother. She said, "I'm not sick. Nothing's wrong with me. Leave me alone. My mother should never have called the crisis team on me. I don't belong here." I was debating with her and trying to, quote, "educate her about her problem." I went and talked to my supervisor 'cause I was frustrated, and she reminded me so much of my brother, and I am telling him the same story I'm telling all of you. My supervisor, I'll never forget really wise guy, wise, not a wise guy, put his hand up and said, "Xavier, stop talking." So I stopped talking. He says, "No, you don't understand. Stop talking to her. Start listening to her. Ask her what she wants. Ask her what she thinks her problem is or problems." So I went back out, and I met with her, and I apologized.

#### (<u>00:10:09</u>):

I said, "I wasn't really listening to you. I was telling you what you needed to do and that you should take medicine. Let's start over, please. What do you want?" She said, "I want to get the heck out of the hospital." Actually, she used a more colorful word than heck, but she wanted to get out of the hospital, big surprise, and she said, "I want my mother to stop calling the police and the crisis teams." I said, "I can work with you on those two things." That afternoon she accepted medication because I told her that was a way we could get her out of the hospital. Within a week, maybe two weeks later, she agreed to meet with her mother and me in the clinic that I was working in as an intern. So that really, it was an epiphany for me in terms of my relationship with my brother, and I called him up and I said a couple of things. I apologized for all the times I told him he was mentally ill. I said, "Henry, I promise I'll never do that again." I kept that promise.



#### Xavier Amador, Ph.D. (00:11:04):

Then I apologized for all the times I told him he needed to take medication and then I promised I'll never again tell you you need psychiatric medications. I kept that promise. Within six months of that shift in me, not in him, the shift in me, he started the change and he accepted a long-acting injectable medication. He stayed on for the rest of his life, nearly 20 years. My brother died, literally being a good Samaritan, was tragically hit by a car in a car accident. But I'll tell you, those 20 years after the shift in how I was talking with him and the shift in our relationship, he stayed in treatment. Our relationship improved. This is a picture of Henry and me. I think a picture is worth 1000 words. The way we're smiling at each other, the way we're holding each other. I'm the one on the left with the Jerry Seinfeld haircut, and Henry was always taller. He was still my big brother. He not only got his little brother back, but he got two part-time volunteer jobs. He had a girlfriend when he passed away.

#### (00:12:17):

He went to a clubhouse to go spend time with, as he put it, "Those mentally ill people, they're really nice." This is real important. He never believed he had schizophrenia. When I asked him, "Well, if you don't have mental illness, why are you taking these shots every month and the medication?" He took some oral meds too, and his answer was very telling, and it's going to relate to the research I'm going to share with you right now and my description of the LEAP program. His answer as to why he was taking medication, even though he knew from his perspective he wasn't sick, was he said, "I do it for you." He named two other people that ran the supported living arrangement that he lived in, the halfway house he lived in. So what was my brother's answer? He stayed in treatment for almost 20 years and did other things, engaged with the clubhouse and worked. He stayed in treatment for relationships, not because he had any insight.

#### (00:13:18):

I'm going to tell you about a little research that shows that my brother is not that unique. Before I do, let's talk for a moment about the media and how it covers stories of people like my brother. It seems like we mostly hear only when crimes have been committed. Here's one of those stories. This is a picture of Margaret Mary Ray, and I'm going to guess most of you don't know who that was. Many of you will remember her as David Letterman's stalker. That's what the newspapers called her. She had the delusion she was married to the celebrity late night TV host. She was certain. It was a delusion. She had schizoaffective disorder. He would come home from the studio in New York City to his mansion in Greenwich, Connecticut and she'd be in the house. She'd break in, and she'd be like, "Well, hi, honey. How was work?" He'd go and call 911 and have her arrested.

#### (00:14:12):

Margaret Mary spent a lot of time under arrest, in courtrooms, on probation, even short stints in jail and never got treatment, never understood that she wasn't married to the man she delusively believed she was married to. Why I'm telling that story is going to be a little bit clearer to you in about 15 minutes. But I have a question for everybody, and Katie's going to put up a poll to see what your answers are. Would you agree with this statement, generally? "Denial of illness impairs your common-sense judgment about the need for treatment and services." Would you agree with that? Yes or no? Let's see what you all think. Does denial impair your common-sense judgment about whether you should be in treatment or not? Okay? 95% of you said, yeah, it impairs your common-sense judgment. Only 5% of you agree with me. I don't think it does impair your common-sense judgment in this way. Bear with me.



#### **Xavier Amador, Ph.D.** (00:15:22):

If I take the perspective of my brother Henry or Margaret Mary Ray, who I just told you about or the millions of Americans with serious mental illnesses, so schizophrenia, a lot of mental illnesses are serious, so I'm using that term shorthand today to talk about people with schizophrenia, schizoaffective delusional disorder, bipolar disorder, those are the main disorders that I'll be summarizing under the serious mental illness. If I take the perspective of Henry, Margaret Mary Ray, and millions of Americans with serious mental illness, it's who don't believe they're ill. It's common sense to refuse treatment. It makes no sense to accept treatment if you don't believe you're ill. This is not a poll, but I have another question for you. I want you to think about it. Would you inject yourself with insulin knowing you don't have diabetes? You're certain you don't have diabetes, would you inject yourself with insulin? I don't need a poll to know the answer. No one's going to do that, right? That's the perspective. That's what it's like to not understand you're mentally ill and be offered treatment.

#### (00:16:29):

It doesn't make sense. It could hurt you, a lot of people tell me. But are we dealing with denial? In most cases, what the research is showing is that we're dealing with a neurocognitive symptom called anosognosia. Let me tell you about the history of this term. It's a tongue twister. Anosognosia has a lot of syllables, but it was this syndrome and this term was coined by the neurologist Babinski in France. He's the same Babinski that discovered the Babinski reflex in infants. With anosognosia, what he described where people, for example, with brain damage, so we're not talking about mental illness, we're talking about neurological disorders, people with brain damage who, for example, had hemiparesis, paralyzed on one side of their body and didn't know it. I've actually evaluated these. I worked at a neurology service for a year. I evaluated people with this symptom, and it's really remarkable.

#### (00:17:30):

How can you not know you're paralyzed? There's one man in particular I asked, "Can you move your arm?" I was assessing anosognosia, and he was paralyzed. He said, "Oh, yeah, I can move my arm." I asked him to move it, it didn't move. Instead of learning that he had paralysis, he accused me of injecting him something in the IV to paralyze his arm. So he didn't understand. I'm going to talk just a little bit more about this syndrome in neurological patients. Before I do, if you want to learn how to say this term, and I think it's really useful to learn how to talk about it, this is the trick I use. A woman named, sorry, Ann is very nosy, so "Ann Knows Egg Nosey Ah, anosognosia. If you're comfortable, I suggest, I'd invite you to say it out loud right now, anosognosia. If you practice it, it's not that hard to say, actually. But let me tell you about one more person with brain lesions, brain damage. This is somebody who was part of a study that I did with my colleagues at Hillside Hospital in Queens.

#### (00:18:45):

You can see the reference down below if you want to look up the article. We were evaluating people with brain damage from stroke, from cancer, from closed head injuries in the frontal lobes of the brain to see if you see anosognosia there. Because the classic descriptions of anosognosia and Babinski's early descriptions was in different parts of the brain, not the frontal lobes. So here's a common task in a neuropsychological test battery. I asked this gentleman, who I'm going to share his picture in a moment, "Can you draw this clock on a scale of 1 to 1? 7 is a perfect copy. 1 is a terrible copy. 3 is okay. What do you think? How do you think you'll do?" I think if I asked you that question, most of us would say a 6 or a 7. We could draw the clock, indicate the correct time. He said, "7, I'll have no problem drawing this clock." Remember, he had frontal lobe damage. Did he have a problem? Clearly. Did he see he had a problem? Not at all.



#### Xavier Amador, Ph.D. (00:19:47):

So I started pointing to the 12s. I pointed to the 12 in the rough circle, and I asked him, "What number is that?" He said, "12." Then I started pointing to those four other 12s outside, and as I kept pointing to them, he got flustered, angry. He pushed the paper away that had the drawing on it and said, "You switched my drawing." So even though he had irrefutable evidence that he had a problem doing this, he didn't learn by that evidence. When I started showing him that he did do an unfortunate poor copy of the clock by showing him all the 12s, he didn't say, "Oh, I see what you mean. I've got a problem." Instead, he got paranoid. He had what's called a confabulation. What are confabulations? Basically, our brain is making up stories to fill in gaps in our memory, or in his case, in his perceptions. So internally, he knew he could do this, but he obviously couldn't and instead of learning, became paranoid and confabulated.

#### (00:20:55):

So when I started my research career at Columbia University on the Schizophrenia Research Center back in 1989, I was real interested in this issue, this problem I'd encountered with my brother and so many patients I worked with during my training. I, with my colleagues, did a big review of the research literature and then we made a proposal to the field. We said, "We need to study this problem, and we think it may be associated with frontal lobe dysfunction. That it's not denial. It's not a result of fear of stigma. It's a frontal lobe deficit." Right away, people went out to test our hypothesis. This is a partial list. If I updated this list, this goes to 2004, if I updated the last 20 years, we'd have six more slides. What are these studies finding? Moderate to strong correlations between executive dysfunction, which is frontal lobe dysfunction and poor insight, people not understanding they had schizophrenia. These are all studies done on people with schizophrenia.

#### (00:21:58):

So what's the headline here? The way the brain is functioning in persons like my brother or Margaret Mary Ray, who I told you about who don't understand they have mental illness, we tend to see what's called hypofrontality, a lower level of functioning, if you will. It's a little bit of a crude way of describing it, in the frontal lobes of the brain. Well, that's how the brain's functioning, how it's working. What about the way it looks? Here's evidence from 20 studies, looking, postmortem studies and brain imaging studies, at the brains of people with schizophrenia who had awareness, had insight, compared to those who did not have insight. All of these studies found significant differences between the subjects who knew they had schizophrenia compared to those who did not know they had it. It was in one or more brain structures, and all of them lay primarily in the prefrontal and frontal cortex of the brain. So here's very compelling evidence between the neuropsychological studies I showed you a moment ago, and now these studies looking at brain anatomy that the brain even looks different.

#### (00:23:06):

Some of the findings, for example, were reduced gray matter. For those of you who know brain anatomy, it's the dorsal lateral prefrontal cortex. So the frontal cortex of the brain was actually showing less gray matter in those subjects who did not understand they had schizophrenia. So the headline is, frontal lobes clearly look different and function differently in people who do not understand they have mental illness. Three of these studies included people who had never been in treatment, so there's two headlines here. One is that the brain differences that were found were not a result of the medications causing brain differences. That's not what was going on. But the other interesting thing is, and we have lots of other research that indicates this, is that first episode, people with first episodes of schizophrenia 18, 17 years old, 21, 25 years old, had these brain differences. Those who did not understand they were ill had different frontal lobes.



#### Xavier Amador, Ph.D. (00:24:14):

So back in 2000, I was one of the co-chairs of the revision of the DSM. The DSM for those of you who don't know is the authoritative diagnostic manual that all mental health professionals use, psychiatrists, psychologists, social workers, nurses, et cetera. Back in 2000 we wrote about anosognosia. But what about the most recent DSM, the one that was published just two years ago? I was asked to submit texts, and it was vetted and peer reviewed by the work group who was revising the DSM Psychotic Disorders and Schizophrenia section. This is verbatim what's in our authoritative diagnostic manual. "Unawareness of illness is typically a symptom. It's not a coping strategy, it's not denial. It is comparable to what we see in neurological deficits following brain damage termed anosognosia." So this is, even though you were very likely encountering a lot of clinicians who don't know about anosognosia, tell them to have a look at their DSM because it's been in that manual for 24 years now, and this is the most recent one from 2022.

(00:25:33): What else did the work group put in the DSM? This symptom, it's a symptom. It's not denial. "This symptom is the most common predictor of non-adherence to treatment." So non-adherence is a term of art. It basically means people who will refuse treatment, or like my brother, accept it, but then drop out typically without telling anyone. So this is the biggest predictor of those problems. It predicts all kinds of other negative outcomes like higher relapse rates, more involuntary treatments and poor psychosocial functioning, so quality of relationships, ability to work, ability to pursue education. All kinds of things have been looked at. Family relationships deteriorate also in persons with anosognosia. The research also found that aggression, that's not violence, it's not physical violence, but it makes sense if everybody around me is telling me, "Xavier, you've got bipolar disorder, you've got schizophrenia," and I don't believe I have it, I'm going to start to get angry. I'm going to start to get, pardon the expression, but pissed off at people. So that's the kind of aggression that the studies are finding. Anosognosia also predicts a poorer course of illness.

(00:26:49): So if you're talking with a healthcare professional who doesn't know, you have a loved one, let's say, with anosognosia, you believe they do point them to page 101 in the manual. I guarantee you they have on their bookshelf the DSM-5-TR. So let's talk just a moment about antipsychotic medications. What do you think the problem is with oral antipsychotic medications, pills and capsules? The problem is, what the research shows is that people either refuse or stop taking them without telling anyone, just like my brother, my finding the bottle of pills in the garbage can. Here's one study. This is representative of many, dozens of study that find very similar rates. The Rummel-Kluge study found that between half to three quarters of people with schizophrenia don't take the medication that they're prescribed or they only take a little bit of it, subtherapeutic doses. This is a longitudinal study done by Sam Keith and John Kane, who's the chair at Hillside Hospital in Queens, New York.

(00:27:58): They followed people over a two-year period and they found that within seven to 10 days of writing a prescription for an antipsychotic medication, 25% of their patients were off the medicine. They stopped with just within a week-and-a-half. 50%, half were off after a year, and 75%, 3/4 of the people in this study were off the medication after two years. This study, both of these studies have been replicated numerous times. Why is that important? It means from my perspective and other scientists like myself, clinicians and scientists, you can take it to the bank. This is a clear, reliable scientific finding. It's a big problem, not adherence to treatment. So what can we do when we're successful in offering treatment? I'm going to talk about that, how to help someone accept treatment. What should we be offering? Long-acting treatments given by injection, long-acting injectables.



#### Xavier Amador, Ph.D. (00:29:00):

In this study, half, like most studies find, on the oral medications, on the pills and capsules stopped taking medication, compared to only 17% on the long-acting injectable medications. So let's flip those numbers around. 83% on the long-acting injectables stayed in treatment, only half on the oral medications. So how do I understand that? If I have anosognosia for my mental illness, and I've got to every day, once, twice, three times a day even put a pill in my mouth and fight my resistance, fight my certainty, "I'm not sick, I don't need this medication," I'm going to eventually throw the pill away like my brother did because my common sense is going to win out. My common sense tells me I don't need treatment 'cause nothing's wrong with me. Longacting treatments given by injection once a month, there's even some that you get only once every three months, so only 12 times a year or only four times a year. Do I have to overcome my resistance if I have anosognosia?

#### (00:30:14):

The other thing is it's a very social administration of medication. You're not alone in the bathroom taking a pill. You go to a clinic, you meet the receptionist. Hopefully, they're friendly with you and you meet the nurse or the PA who's going to give you the injection. Also, intuitively, it's a smoke detector. If somebody misses an injection appointment, you can talk with them and see if you can help them to make a new appointment. I'm going to tell you about some videos that are free that you can access. One of them is exactly about this scenario. A young man with schizoaffective disorder misses his appointment for an injection, and his doctor calls him and they have a conversation using the LEAP Approach, which I'll be introducing you to. The other thing is it reduces tension. As a family member or as a clinician, we often are in the position of having to ask, "Well, are you taking the medication?"

#### (00:31:08):

I don't have to ask that question anymore and put my patients, or in the case of my brother, in the uncomfortable position of not wanting to tell me that they've stopped. So I just know one way or the other if they're in treatment, so it reduces tension. Then the third intuitive benefit to this kind of treatment is you can use relationship. You can use techniques like the LEAP Approach to help somebody change their mind and make a new appointment. Again, there's a video that you'll be able to see that, that shows that scenario if you're interested. So let's summarize. What do we know about awareness of having an illness and treatment adherence, acceptance of treatment, staying in treatment? Well, awareness of being ill is the top predictor. It's among the top two predictors of who will stay in treatment long-term like my brother did for nearly 20 years. What do you think the other top predictor is?

#### (00:32:02):

Katie has one more poll for you and you're going to have three choices, three options to choose from and just take a moment. What do you think the other predictor is? This is in patients with anosognosia who do not understand they're ill. What's going to predict their accepting treatment and staying in treatment long-term just like Henry did? There's a hint in that comment, by the way, 'cause of what Henry said. Side effects, past experience with medication supportive relationships. So side effects, about 12% of you. When I looked at the research, I thought that it was going to be side effects. It turns out side effects don't predict who will refuse treatment. I have borderline high blood pressure. First medication I got from my doctor made me dizzy, gave me what's called orthostatic hypotension. I didn't throw away the blood pressure medication and refused all treatment. I went back to my doctor and said, "Hey, can we try something else?"



#### Xavier Amador, Ph.D. (00:33:00):

So it's not side effects or past experience with medications. It is a kind of relationship, but not just a general supportive relationship. It's a relationship. This next part I'm going to show you is a summary of research on therapeutic alliance. Someone listens to you without judgment. So when I say to somebody, let's say, I've got schizophrenia, "I'm not ill, I don't have schizophrenia." The person that's talking to me is actively listening and saying, "So what you're telling me is you don't have schizophrenia, and you don't need this medicine. Is that right? Did I understand you?" So it's a respectful non-judgmental communication, and I'm going to give you a little bit more examples of that in a minute. So respectful, non-judgmental, and they'd like to see you in treatment, those are the three characteristics of a relationship that leads to treatment engagement, staying in treatment as well.

#### (00:33:58):

So to summarize everything I've been through here so far, that I've been talking about, what do we know about anosognosia for mental illness and acceptance of treatment? We never win on the strength of our argument of providing evidence, "You've got a problem. You've got mental health condition." It doesn't work if the person has anosognosia. We win on the strength of our relationship, respectful, non-judgmental communication. So summary of what I reviewed, the research. Anosognosia often called poor insight into having a serious mental illness is a neurocognitive symptom. It's not denial. It tends to be stable over time. I didn't mention that research in the interest of time, but our field has looked at the research, two-year periods even. In most people, like my brother, when successfully treated, it turns out the anosognosia usually doesn't improve. So we really have to come up with a different way to engage people in treatment.

#### (00:34:58):

It's not like let's get them in the hospital and treat it and fantastic, they're going to have insight and stay in treatment. That's not the typical story. It's, typical story is the one I told you about my brother. He never understood he had schizophrenia, yet he stayed in treatment for a long time. It is the top predictor. Anosognosia is the top predictor of treatment refusals and dropouts, predicts higher number of hospitalizations, poorer psychosocial functioning and lots of other negative outcomes. It's just a barrier to creating a partnership, a working alliance with the person. So when you're talking about anosognosia, just one more comment about this, how we talk about it really matters 'cause it impacts how you're going to behave, how you're going to communicate and what you're communicating to the rest of the family.

#### (00:35:48):

So try not to say things like, "She does not accept she has an illness," because that indicates that we think the person has a choice and they're just not accepting it, or, "He refuses to acknowledge he has mental illness." Would you ever say this about somebody that they refuse to stop hallucinating? Would you do that? No, and why not? Because you know it's a symptom. It's not under their control. Well, so is this lack of insight, this anosognosia. Nobody's refusing anything, they just can't understand. Denies she has an illness, doesn't admit as if the person really knows, but they're being stubborn and they're not going to admit it. Won't admit, refuses to admit that they have mental illness. If you come away from today convinced that this is a real symptom, this anosognosia, this unawareness, I encourage you not to use this kind of language.



#### Xavier Amador, Ph.D. (00:36:51):

What kind of language can you use? Things like, "She cannot comprehend," not because of intelligence, but because of this neurocognitive symptom of anosognosia, can't comprehend she has an illness. "He's unaware he has mental illness, unable to see or understand that she has mental illness." Ideally, and I'm starting to see this in medical records, thankfully, 'cause there's so much research indicating this is a real symptom, has anosognosia for mental illness. That's ideally what we'd be saying, "Can't comprehend, is unaware, unable to see, has anosognosia for mental illness," rather than things like, "Refuses to acknowledge." So boy, I've covered a lot pretty quickly about anosognosia for mental illness, but what does it feel like? Katie and NAMI has given me the opportunity to do a role play with you, not with all of you, obviously.

#### (<u>00:37:54</u>):

We're going to need a volunteer. This is real important. Please pay close attention. If you've seen me do this role play where I'm going to talk to you about your spouse, please don't volunteer. That's real important. So to volunteer, you got to have a webcam that you're willing to turn on. Remember, this is being recorded, so hopefully you'll be comfortable with that, and you are married, currently married, and you are currently working. That's really important for this role play to work. Okay? You got a webcam, you're willing to turn it on and you're married and you're working, go to the reactions button at the bottom of your screen and press that little yellow hand. Katie is literally randomly going to pick someone, and you and I are going to talk together for a few minutes. Katie, you're still with me, right?

#### **Katie Harris** (00:38:54):

I am. I'm working on promoting someone. Just one minute.

#### Xavier Amador, Ph.D. (00:38:59):

Okay. I didn't mean to rush you, sorry. Bernadette, I think we've got a volunteer, and if you could unmute yourself and turn your video on. Oh, we've got two volunteers. Kimberly or Bernadette? It's Bernadette. How you doing?

#### Bernadette Moore (00:39:29):

I'm good, thank you.

#### Xavier Amador, Ph.D. (00:39:32):

Nice to meet you, and thank you for volunteering. I really appreciate it.

#### Bernadette Moore (00:39:34):

Oh, my pleasure.

#### **Xavier Amador, Ph.D.** (00:39:37):

Bernadette, what's the name of your spouse, first name?

#### Bernadette Moore (00:39:40):

James. I call him Jim.

#### Xavier Amador, Ph.D. (00:39:43):

Okay, Jim. Your supervisor at work, what's their first name? I forgot.



#### Bernadette Moore (00:39:47):

Kirsten.

#### Xavier Amador, Ph.D. (00:39:49):

Kirsten, that's right. This is awkward, Bernadette. This is not the LEAP Approach I'm going to be introducing, but I was asked by Jim and his wife, who's not you, his wife, Susan, to try and help you today, to do an intervention. Your supervisor, Kirsten also asked me to tell you that she's putting you on a six-month leave of absence. The reason for that is not only are you not married to Jim, I know you think you are, how long do you think you've been married to Jim?

#### **Bernadette Moore** (<u>00:40:28</u>):

Too long.

#### Xavier Amador, Ph.D. (00:40:30):

Too long? 20 years?

#### **Bernadette Moore** (<u>00:40:31</u>):

Yeah, 22 years.

#### Xavier Amador, Ph.D. (00:40:35):

That's what I heard from him. Do you believe you have kids together? I forget.

#### Bernadette Moore (00:40:39):

No.

#### **Xavier Amador, Ph.D.** (00:40:40):

No, okay. I wasn't clear. Anyway, look, they contacted me before this seminar and like I said, Katie was good. Katie was hoping you were going to volunteer so that we could pick you. I have restraining orders that I can email to you showing that you clearly are stalking. Just like Margaret Mary Ray did with David Letterman, you're stalking this poor man, Jim and his wife Susan, and to stay away restraining order. If I showed you those, would that convince you that you're not married to Jim? I don't think so, right?

#### **Bernadette Moore** (<u>00:41:14</u>):

No.

#### **Xavier Amador, Ph.D.** (00:41:14):

All right. Well, the good news, you're at work right now, right?

#### **Bernadette Moore** (<u>00:41:17</u>):

Right.



#### Xavier Amador, Ph.D. (00:41:18):

Yeah. Well, Kirsten told me to let you know that right now, you're on a medical leave of absence until she gets a report from a treating psychiatrist that you've been in treatment and that you're no longer going to harass Jim and his family. I'm going to ask you to get up and go and speak with, we've got a mobile crisis team, a mental health crisis team outside the front door of the offices. They're willing to talk with you. You're not a danger to yourself or others as far. As we know you're okay with that, but they'd like to talk with you and maybe offer to help you. Would you be willing to get up and go outside and talk with them?

#### Bernadette Moore (00:42:01):

I probably would because I'm afraid of losing my income.

#### **Xavier Amador, Ph.D.** (<u>00:42:05</u>):

Yeah. Well, you're going to have to leave. So let's imagine you go out there and you're talking to them and they say, "Ms. Moore, we'd really like to offer you a hospitalization or at least an evaluation in an emergency room, would you be willing to come with us? We think you might have a problem here with this belief you're married to this man, Jim." Would you go to the hospital and get evaluated?

#### Bernadette Moore (<u>00:42:34</u>):

I guess to prove that I'm not ill.

#### Xavier Amador, Ph.D. (00:42:34):

Okay, so they take you to the hospital, you're in the ER. The doctor evaluates you, and she says, "Well, I think you'd really benefit from an admission to our unit, our psychiatric unit upstairs, our behavioral health unit. Would you be willing to go? Now I can't hold you."

#### Bernadette Moore (00:42:49):

Yeah.

#### Xavier Amador, Ph.D. (00:42:51):

Okay, so you're going to leave?

#### Bernadette Moore (00:42:52):

Pardon me?

#### **Xavier Amador**, Ph.D. (<u>00:42:54</u>):

You're going to leave against medical advice, right? You're not going to go upstairs?

#### Bernadette Moore (00:42:59):

No, I don't want to be hospitalized.



#### Xavier Amador, Ph.D. (00:43:01):

Okay, so the doctor says to you, "Ma'am, that's your choice. We wish you the best. I wish you'd change your mind. If you do come back and talk to us." You go out into the lobby of the hospital, where do you go? What do you do? Who do you call?

#### Bernadette Moore (00:43:15):

Well, I would hope that they would direct me to somebody that I could go to out of patient.

#### Xavier Amador, Ph.D. (00:43:22):

Okay, but where do you go to while you're waiting for that appointment?

#### Bernadette Moore (<u>00:43:27</u>):

Oh.

#### **Xavier Amador, Ph.D.** (00:43:27):

Where do you go?

#### Bernadette Moore (00:43:28):

I see what you're saying, 'cause I don't have a place to live? Is that what you're saying?

#### Xavier Amador, Ph.D. (00:43:34):

You're not going to test that out.

#### Bernadette Moore (<u>00:43:37</u>):

I'm sorry?

#### **Xavier Amador, Ph.D.** (00:43:38):

All you have is me in this meeting telling you you're delusional, and you've got a doctor in an ER and a crisis team telling you you're delusional, do you think you're delusional? Do you remember getting married the Jim? You remember your wedding day?

#### Bernadette Moore (00:43:51):

Yeah.

#### Xavier Amador, Ph.D. (00:43:53):

Yeah. Do you really think you could be convinced that quickly that it didn't happen?

#### Bernadette Moore (00:43:57):

No.

#### **Xavier Amador, Ph.D.** (00:43:59):

Okay. So you're outside the hospital, do you go home or do you call Jim?



#### Bernadette Moore (00:44:05):

I would go home.

#### Xavier Amador, Ph.D. (00:44:06):

Okay, so when you go home-

#### Bernadette Moore (00:44:06):

[inaudible 00:44:07]

#### Xavier Amador, Ph.D. (00:44:09):

Okay, so you go home, where Jim lives. Your key doesn't work, guess what happens? You get arrested.

#### Bernadette Moore (<u>00:44:14</u>):

Okay.

#### Xavier Amador, Ph.D. (00:44:16):

You're brought before a judge. Now I'm the judge, "Ma'am, we've got a mental health diversion court. I've got two charges. Criminal trespassing and violation of a restraining order. I'm going to give you a choice. We can go to trial on those two charges or we have a pretrial mental health diversion program, and you can go with our social worker, court personnel in the back of the courtroom here and go to a hospital and get evaluated. What would you like to do?" I'm the judge. I'm giving you a choice. "Go to trial or go to treatment. What do you want to do?"

#### Bernadette Moore (00:44:50):

I guess I'd go to treatment.

#### **Xavier Amador, Ph.D.** (00:44:54):

"Great. I wish you the best, ma'am. I'm looking for a report from your treating psychiatrist in 30 days, another one in six months, and we can expunge these charges, dismiss the case. I wish you the best of luck." That's what the judge says. So you go to the emergency room and the same thing happens. You see the same doctor and she says, "Would you like to get admitted to the psych unit?"

#### Bernadette Moore (00:45:16):

Well, I guess-

#### **Xavier Amador, Ph.D.** (00:45:16):

It's your choice. You're not a danger to anyone. It's your choice.

#### **Bernadette Moore** (<u>00:45:21</u>):

Well, is it court ordered because-

#### Xavier Amador, Ph.D. (00:45:23):

No, ma'am. It's your choice.



# Bernadette Moore (00:45:24): No? Xavier Amador, Ph.D. (00:45:25): No. Bernadette Moore (00:45:26): Wow, you can't Xavier Amador, Ph.D. (00:45:27): We can't force you, no. The judge is giving you a choice. Go into the criminal justice system, go to trial or go get some help. Now they're offering you the help. What do you say? Do you want to get admitted to the unit?

**Bernadette Moore** (<u>00:45:43</u>):

Well, there's a lot of factors here, because in my mind, I still live home with Jim.

**Xavier Amador, Ph.D.** (00:45:51):

That's right.

Bernadette Moore (<u>00:45:53</u>):

You're saying my delusion or I don't live with Jim-

**Xavier Amador, Ph.D.** (<u>00:45:57</u>):

Bernadette? Bernadette?

Bernadette Moore (00:45:58):

... so where do I live?

**Xavier Amador, Ph.D.** (<u>00:46:00</u>):

It's not just me saying it. Kirsten, your boss is saying it. Jim is saying it 'cause he's got restraining orders against you. The judge is saying it. The crisis team is saying it. The doctor in the ER, Everybody's telling you you've got a delusion about Jim, you're mentally ill. So here's the question again. Do you go up to the hospital or do you walk out of the emergency room? It's okay if you want to walk out, that's your choice. What do you do? What do you think you'll do?

**Bernadette Moore** (<u>00:46:26</u>):

Part of me wants to fight it.

**Xavier Amador, Ph.D.** (00:46:27):

Okay.

Bernadette Moore (00:46:28):

I'm like, "I'm going to call my best friend and what's going on? Maybe they could talk to me."



#### Xavier Amador, Ph.D. (00:46:33):

You know what your best friend says, Bernadette?

#### **Bernadette Moore** (<u>00:46:37</u>):

What?

#### Xavier Amador, Ph.D. (00:46:38):

"Please get help. I've been so worried about you and this wacky idea you have that you're married to Jim."

#### Bernadette Moore (00:46:44):

Wow. That would turn me around because I trust my friend.

#### Xavier Amador, Ph.D. (00:46:52):

Really?

#### **Bernadette Moore** (<u>00:46:55</u>):

Yeah.

#### **Xavier Amador, Ph.D.** (<u>00:46:56</u>):

As you think back on the last 22 years, you think your friend, that one comment would convince you you never got married to Jim? You haven't shared your life together for these two decades? One comment?

#### Bernadette Moore (00:47:18):

I don't guite understand the guestion.

#### Xavier Amador, Ph.D. (00:47:22):

Could you be convinced you're not married to Jim?

#### Bernadette Moore (00:47:24):

Because of her comment?

#### Xavier Amador, Ph.D. (00:47:25):

Mm-hmm.

#### Bernadette Moore (00:47:27):

No, I would go because she said she's worried about me. Then I might say to myself, "Well, maybe there is a problem."

#### **Xavier Amador, Ph.D.** (<u>00:47:38</u>):

So you'd go get some treatment?



#### Bernadette Moore (00:47:40):

I would go start with questions.

#### **Xavier Amador, Ph.D.** (<u>00:47:43</u>):

Okay. So here's what happens. We're going to wrap this up, okay? Every time you text Jim or call Jim or try to see him, you get back into this cycle. You're arrested. You're brought before a judge. The judge offers you treatment or trial, and this goes on for a year. You cannot contact Jim without this happening for a year. Do you think after a year you'd finally come to your senses that you were never married to Jim you'd be convinced?

#### **Bernadette Moore** (<u>00:48:25</u>):

I don't know.

#### Xavier Amador, Ph.D. (00:48:25):

Really?

#### Bernadette Moore (00:48:27):

If I went for treatment to find out about why I think that way and everyone is convincing me that I'm not married to him, but for a year I've been told this, I guess I would maybe think about it at least or say, "I'm tired of this. Why bother?"

#### Xavier Amador, Ph.D. (<u>00:48:49</u>):

Let me ask you this. Do you remember your first date with Jim?

#### Bernadette Moore (00:48:52):

Yeah.

#### **Xavier Amador, Ph.D.** (00:48:53):

You remember your wedding day?

#### **Bernadette Moore** (<u>00:48:55</u>):

Yeah.

#### Xavier Amador, Ph.D. (00:48:56):

Think of those memories. Are you really saying you could be convinced that never happened?

#### Bernadette Moore (00:49:00):

In my mind they happened.

#### Xavier Amador, Ph.D. (00:49:09):

That's right. That's what it's like to have anosognosia for mental illness. No matter what kind of experiences the person has, no matter who's telling them that their reality is false, they know their reality. You know you're married to Jim. You've been together for 22 years. So those experiences aren't going to educate you. That's what it's like to have an anosognosia. So I have one more question. Can I ask you one more question?



## Bernadette Moore (00:49:36): Mm-hmm. Xavier Amador, Ph.D. (00:49:37):

What did it feel like as you imagine this happening to you? Any feelings?

Bernadette Moore (<u>00:49:44</u>):

Overwhelmed.

**Xavier Amador, Ph.D.** (<u>00:49:47</u>):

Overwhelmed.

Bernadette Moore (<u>00:49:48</u>):

To even think of that possibility of not being able to walk into my house, to not have the life I thought I had.

**Xavier Amador, Ph.D.** (<u>00:50:01</u>):

Right.

**Bernadette Moore** (<u>00:50:02</u>):

Yeah.

**Xavier Amador, Ph.D.** (00:50:03):

How about scared or angry or both?

**Bernadette Moore** (<u>00:50:06</u>):

Both, and also now I don't have a job-

**Xavier Amador, Ph.D.** (00:50:10):

That's right. Unemployed.

Bernadette Moore (00:50:11):

... or a place to live if that was the case.

**Xavier Amador, Ph.D.** (00:50:17):

And if this went on for five years, Bernadette, would you start to feel pretty depressed and isolated, do you think-

Bernadette Moore (00:50:22):

Oh, sure.

Xavier Amador, Ph.D. (00:50:22):

... cause everyone's telling you... Yeah. Okay. Bernadette, two things. Thank you very much for volunteering.



#### Bernadette Moore (00:50:31):

My pleasure.

#### Xavier Amador, Ph.D. (00:50:32):

When you get home, go give Jim a big hug.

#### **Bernadette Moore** (<u>00:50:34</u>):

I will.

#### **Xavier Amador, Ph.D.** (<u>00:50:37</u>):

This was a role play, everybody. Bernadette is married to Jim.

#### **Bernadette Moore** (<u>00:50:41</u>):

Yes.

#### Xavier Amador, Ph.D. (00:50:43):

Thank you so much for volunteering and helping us out.

#### **Bernadette Moore** (<u>00:50:45</u>):

Oh, and thank you for all you do. We teach you a lot. I'm in the IFSS Program in Cape May County, and we brought your book in. We've presented it to our families, and we have quite a few that have followed it and they've had good results from it.

#### Xavier Amador, Ph.D. (00:51:02):

I'm glad.

#### Bernadette Moore (00:51:02):

So we want to thank you too for what you've helped and we've presented. So anytime you want to come in and talk to our families, you're always welcome.

#### **Xavier Amador, Ph.D.** (00:51:15):

Okay. I'm going to move on, but thank you so much.

#### **Bernadette Moore** (<u>00:51:17</u>):

Okay.

#### **Xavier Amador, Ph.D.** (00:51:18):

Thank you for the kind words. I'm glad my work's been helpful. Thank you so much. Katie, can I move on, or I see Teri has her hand up, Teri Brister.

#### Teri Brister, Ph.D. (00:51:28):

Sorry, I was trying to applaud Bernadette. Excuse me, doctor.



#### Xavier Amador, Ph.D. (00:51:31):

Okay, thank you. Thanks very much. I'm glad it's helpful, I really am. So listen, when we're helping someone with anosognosia, let's say we're trying to help Bernadette. If she really was delusional, the parent knows is the expert and has good information or the sibling or the doctor, it doesn't work because we're not collaborating. Bernadette, I'm sure wasn't grateful for my diagnosis that her marriage was a delusion or receptive or adherent. She was trying to escape treatment. What we can expect, look at the feelings that are up there, some of them, she talked about being overwhelmed, scared, angry, depressed, we can expect those feelings, frustration, anger, hostility, fear, loneliness, depression and isolation and non-compliance with treatment, non-adherence, refusing treatment, 'cause why would you take pills for an illness you were sure you didn't have? So I'm going to just end with giving you just a quick overview of the LEAP Approach.

#### (00:52:36):

This is in the book that Bernadette answered. There are free chapters. If you don't want to buy the book, I'm okay with that. There are free chapters on the NAMI website. I think we have five chapters that I donated up there. This program was selected by SAMHSA, the Substance Abuse Mental Health Services Administration for their Family Toolkit. It's focused on developing relationships that lead to treatment. There are seven tools listed on the left side of your screen. I'm going to summarize them for you. We listen by reflecting back without judgment. Remember what I talked about earlier, the research, non-judgmental, respectful relationship. We empathize especially for feelings coming from if the person's delusional, they're delusions. The anosognosia, the anger, the frustration, the sadness that nobody believes me. Those are feelings that come from anosognosia. We empathize with those feelings in particular and the desires of the person.

#### (00:53:33):

We focus on areas where we can agree. We are not going to agree the person has an illness. If they have anosognosia, that's not possible. So you got to forget that goal and do something real different. Stop educating, start listening. Look for areas where you agree so you can partner. That's what you move forward on to achieve common goals that you both agree can be worked on. This is not in the LEAP acronym, there's three more letters, DOA. It sounds unfortunate, but we believe that our relationships are dead on arrival if we're not communicating in this respectful way, so we delay giving hurtful and contrary opinion. So if Bernadette asked me, let's say I'm working with her, I'm a probation officer two years down the road, "Hey, do you think I'm married to Jim?" I might try to delay answering that, "Hey, I could be wrong, and I'm sorry I think this, I hope you don't have to argue about it. I don't see that you are married to Jim. There's three As, I'm sorry that's giving our opinion. I jumped ahead.

#### (00:54:36):

"I could be wrong and I'm sorry, but I don't think you're married." There's a way of giving our opinion in the LEAP Approach that's very humble. To delay giving our opinion, we say things like, "I promise I'm going to answer your question. Before I do, can you tell me more about..." and we get the person talking some more, and we ask permission, "Can I tell you later?" So that's delaying and giving our opinion. Then we apologize for acts and interactions that felt disrespectful, frustrating or disappointing. This is just like learning a new language, practice makes perfect. Role play with your loved ones or colleagues at work. I'm going to share some videos with you in just a moment, how you can access them so you can practice with the videos. So this is, I'm going to end on just general guidelines. Those are tools, those L-E-A-P D-O-A. Those are tools.



#### **Xavier Amador, Ph.D.** (00:55:26):

These are steps. First, we absorb what we've heard, and that usually involves active, reflective listening. So again, if I was talking with Bernadette, I'd say, "So Bernadette, what you're telling me is you're married to Jim, but nobody believes you anymore. Is that right? Did I get that right?" That's active, reflective listening. Then I want to emotionally connect by empathizing or apologizing, like, "I'm sorry that that's happening to you." I'm going to read some of the feelings Bernadette described that, "It sounds like it feels very overwhelming and you're frightened and depressed and angry about this. Did I get that right?" So we want to connect with their experience and absorb it. Then you can start to problem solve. Then you find areas of agreement and partnering, like I did with my brother. He wanted pocket money. I said I'd give it to him in exchange for his agreeing to see a therapist and eventually, receiving these longacting injectable medications.

#### (00:56:23):

There's a lot more detail there, but we don't have the time right now to get into it. We use each of these tools as you need them. Think of a tool belt, and you've got those seven communication tools in there. So that's an overview. There's a lot more. Thank you, Bernadette. Thank you, everybody, for your attention and involvement. Before I sign off, if you've got a phone and you want to go to our website, just put your camera up on that code to the right, and that leads you right to leapinstitute.org. When you're at leapinstitute.org, there's a tab called Resources Free Videos. You're going to find all kinds of videos that are role plays, that are talks that I've given. There's a TED Talk if you want to educate family or clinicians or colleagues about anosognosia, we got a lot of good feedback about that. So thanks again. I'm sorry I ran a little long, but I will turn it back over to Dr. Duckworth.

#### Ken Duckworth, MD (00:57:21):

Dr. Amador, brilliant talk. Fantastic. So with 3,700 people on a call, you can imagine we have a lot of questions, about 50 questions on medications. I might take one or two of them later on to give you a break.

Xavier Amador, Ph.D. (00:57:36): Okay.

#### **Ken Duckworth, MD** (00:57:36):

We have a conversation on managing antipsychotic side effects, long-acting injectables, that'll be coming. Side effects in pregnancy of medications, we have an expert covering that on March 7th. So let's focus on your area of brilliance, which is forming relationships. So a couple of questions fall into the category of, "My loved one. Is non-communicative or we've had a rupture in our relationship." How might you proceed in those ways?

#### **Xavier Amador, Ph.D.** (<u>00:58:08</u>):

So there's two things. This comes up a lot, and I call it opening closed doors. First, try to see if you can figure out what it was that caused the disengagement, the rupture. Usually, in my experience, it's conversations about telling the person that they need medicine or an involuntary hospitalization. So the first step is to apologize like I did with my brother, "I'm sorry for all the times I told you you were mentally ill. I won't ever do it again." Apologize for an involuntary hospitalization if that's what's happened, and then really importantly, start listening actively. Ask the person what they're upset about, what they're angry about. Why aren't they talking to you? Now, sometimes they're not talking to us because they have a delusion about us.



#### Xavier Amador, Ph.D. (00:58:56):

Don't be afraid to reflect that back. So I'm working with a family right now where their son is convinced that the parents have been poisoning him. I'm practicing with them just reflecting that back, "Son, what you're saying is we've been trying to hurt you, even kill you. Did we get that right?" I know that sounds counterintuitive, but that starts a conversation with the person where you can use those other tools to emotionally connect with them. If the person's not communicative, I can't believe I'm going to say this because my teenagers drive me nuts with all the texting, but texting is actually really effective. If the person will accept your texts, you can start with an apology with the thing you think they're angry with you about, and then do active listening in the text messaging.

#### Ken Duckworth, MD (00:59:46):

Thank you. Another set of questions gets into the idea, "Because I'm being accused of doing horrible things, how do I get into the place of being empathic and working towards agreement?" Most people don't like those responses, and I can recall this in my own family experience. You have a natural limbic response to being accused of horrible things. How do you transcend that normal human response?

#### **Xavier Amador, Ph.D.** (01:00:15):

It's a really, really great question. The number one first thing we have to do is separate the illness from the person. So remember what your loved one was like before the illness and how they never would've accused you of the horrific things they're accusing you of now, and realize it's not your loved one who's making the accusation, it's chemical chaos in their brain. It's the illness talking to you. So that's the number one thing. Don't take it personally. Don't get confused. This is the illness talking to you. Then the other thing is, and again, we don't have time, Ken, to get into it in detail, but I'll just say in broad strokes.

#### (01:00:58):

You want to absorb what they're saying, those three steps I shared. "So what you're saying, son, is we sexually abused you when you were an infant. I can see why you're angry with us." Then it sounds scary because you're going to make things worse. Well, if somebody has a delusion, it's a fixed false belief, you're not going to make the delusion worse. So creating that bridge and the research indicates that fundamental pillars of that bridge is respecting the person's reality, their experience, not telling them they're wrong. Now, you do give your opinion with the LEAP Approach.

#### (01:01:34):

If they push and they want to say, for example, want you to admit, "Admit that you did it, Admit that you really did abuse me," you can answer that question in the way that we teach it. Those three A's: apologize, acknowledge your fallibility, ask the person not to argue, agree to disagree. So you could say something like, "I'm really sorry. I appreciate your opening up to me about the abuse. I could be wrong. I don't think I'm wrong, son. I don't remember ever doing anything like this. I hope we don't have to argue about it," and that's it. You're still stating your truth, that you didn't do anything wrong, but you're not saying it in a sparse way. "I didn't do that. I would never do that to you." That's not going to get you anywhere. If you can say, "Hey, I'm sorry. I don't see that I did this, and I don't want to argue with you about it," that's more respectful.

#### Ken Duckworth, MD (01:02:30):

But I have heard you.



#### Xavier Amador, Ph.D. (01:02:32):

But I've heard you, right.

#### Ken Duckworth, MD (<u>01:02:33</u>):

I've heard what you've said. I'm not denying that you experienced this.

#### **Xavier Amador, Ph.D.** (01:02:38):

Yes. What's really important, Ken, with the LEAP Approach is you ask the person, "Do you feel like I understand you?" Because if the person says, "I don't think you do," then you start over. But yeah, that is the critical piece is that your loved one feels heard and that the reality isn't being dismissed, out of hand. But you don't agree. The LEAP Approach is 100% honest. You never pretend you did something that you didn't do. That's real important.

#### Ken Duckworth, MD (01:03:07):

Okay, great. Another question gets into this question of supporting versus the question of enabling.

#### Xavier Amador, Ph.D. (01:03:14):

Okay.

#### Ken Duckworth, MD (01:03:15):

Right? So you're not reality testing the person. You're not saying, "That isn't true. The FBI is not at the door."

#### Xavier Amador, Ph.D. (01:03:23):

Right.

#### Ken Duckworth, MD (01:03:23):

Then if you don't do that, the question of, "Am I enabling, am I facilitating a belief?" When is support one is empathic and what is enabling? I know these are hard questions, but you're the master of this entire field, so I'm going to give you the hard ones.

#### Xavier Amador, Ph.D. (01:03:41):

Emphatically, no, you are not enabling. You are not enabling. When somebody has a psychotic disorder, they have false perceptions, seeing things, hearing things, sometimes even feeling things that aren't there. You're not going to make that worse in the ways that you communicate with the person. Same thing with a delusion. A delusion is a fixed and concrete false belief. You're not going to make it worse by helping the person to feel heard and understood. That builds trust that these illnesses and our inability to communicate effectively erodes, so we want to rebuild that trust. The number one way to do that is to respect and empathize with your loved one's experience. You're not going to make their psychotic symptoms worse. It's not possible.

#### Ken Duckworth, MD (01:04:38):

So again, you go back to the quality of the relationship. That's your North Star.



#### Xavier Amador, Ph.D. (01:04:44):

Yes. Yes.

#### Ken Duckworth, MD (01:04:45):

Thank you. All right, next level of complexity, "My family members interacted with the treatment system, and they want to have me be the guardian, involuntary hospitalize him, inject medicines into him in the hospital against his will," variations on this theme of a non-LEAP in engagement, or even the psychiatrist saying, "Bob, you've got to take your meds," in the clinical room. Then the person comes home and they're not having that LEAP experience integrated into the [inaudible 01:05:20] How do you approach that problem?

#### Xavier Amador, Ph.D. (01:05:25):

With a lot of empathy and even apology, like, "I'm sorry that this is the situation we're in and that I have this responsibility now. A third of the I Am Not Sick; I Don't Help book is all about involuntary treatments. Most of it is about anosognosia and LEAP, but sometimes that's not enough. We are in a situation where we are in a court- mandated treatment, for example, so you do it with a lot of empathy. "If I was in your place, son, I had be really angry about this too. I know I testified at the hearing, and I hope you can forgive me." If you're comfortable with it, a statement of fallibility, "Maybe I was wrong to do that. I just was following my heart, and I thought it was the right thing. I respect your truth. This is active, reflective listening, "You're telling me, son, that you're not mentally ill and this court order is a traumatic travesty of justice," right?

#### Ken Duckworth, MD (01:06:32):

Right.

#### Xavier Amador, Ph.D. (01:06:32):

"I can see why you're angry." There's reflective listening and empathy. "Well, then why are you doing it, dad?" "I just thought it was the right thing to do and I'm sorry. I don't want to argue with you." So that's the nature of the dialogue. You want to apologize. You want to be empathic. You want to actively listen.

#### Ken Duckworth, MD (01:06:50):

For those of you interested, I'm going to give you a break. You could just take a deep breath. Dr. Amador, you've done a tremendous presentation. I'm going to try to address a few of the other questions; questions about research, brain scans, genetics. We had Jordan Smoller, who's running a million-person, All of Us genetic biology in research program. That is on Ask the Expert, that's our website. Katie Harris, who's our star facilitator and producer will give you both these slides, but also all the presentations where we try to attract the best thinkers in the field, the entire field. So those questions have been answered by people who are actively working on it. Long-acting injectables have the same side effects as oral medications. They are, in fact, the same medicines, they just stick around in your fat. So I just wanted to mention that, and there is no brain scan that you can test for anosognosia, and there is no way to identify that a brain change has occurred. Dr. Amador, do you disagree with anything that I mentioned right there?



#### **Xavier Amador, Ph.D.** (01:08:02):

100% agree. I will say one thing, I get asked the question all the time, "How do you know it's anosognosia?" It's actually very intuitive. If the person you're trying to help, your loved one has had ample opportunity to learn they have a mental health condition and it's gone on for a month, several months, a year or longer and they have not learned, they have not developed insight or awareness, you're dealing with anosognosia. You don't need a brain scan. It's common sense, intuitive.

#### Ken Duckworth, MD (01:08:37):

There's a question about the episodic versus permanent nature of anosognosia, and I happened to see in my own childhood my dad would become psychotic with a manic episode, then not have anosognosia. But he then had denial about the illness process. He lived with both of these things. I just wanted a normal dad, so I lived with denial. He would get out of the hospital. We'd go to the Tigers game. I was happy. I didn't take it up with him for many reasons, but mostly, I just didn't want to take it on 'cause I had this intuition that it wasn't going to work. What about permanence versus the course of delusions? Do they improve with medications for some people? How do you think about the process of anosognosia? I know it's individual, but I'm interested in your answer to this 'cause it's come up in multiple questions.

#### **Xavier Amador**, Ph.D. (01:09:34):

Well, I can answer it clinically, my clinical experience with now thousands of people with these illnesses. But let me start with the research. What's the evidence base? What the research shows is that with schizophrenia, it tends to stay stable in most patients. But that's most patients, the majority of patients. Like my brother, he never developed awareness. But there's a smaller proportion, about 10 to 15% who with treatment, the anosognosia improves along with the other psychotic symptoms, but the majority don't. Now, bipolar disorder like your dad had is different. Anosognosia is exacerbated. All right? It's exacerbated during the manic phase. During the euthymic phase, in other words, stabilization phase or when the person has depression, the anosognosia tends to remit a bit and the person has the ability to understand. That doesn't mean denial can't kick in. That's another whole layer.

#### Ken Duckworth, MD (<u>01:10:37</u>):

Right.

#### Xavier Amador, Ph.D. (01:10:38):

But anosognosia in itself, let me summarize succinctly, with schizophrenia, tends to not improve with treatment. With bipolar disorder, it tends to improve the treatment. But you got to keep your eye on the ball because it can still exist at a mild level and be encouraging the person silently, "Well, I'm feeling better. I can go off the meds now." So you want to keep an open dialogue about the person's understanding of whether they have an illness or not.

#### Ken Duckworth, MD (01:11:08):

Well, this has just been a fantastic presentation. Everyone who registered will get this presentation they can watch. You will get the slides. Dr. Amador has made himself available. You can connect with him through the Leaf Institute or the Henry Amador Center. I just want to thank Bernadette for volunteering.



#### Xavier Amador, Ph.D. (01:11:28):

Yes. Thank you.

#### Ken Duckworth, MD (01:11:29):

Thank you. Fantastic job, Bernadette, rather stressful what the good doctor put you through. But mostly, I want to thank you for this presentation and for helping deal with one of the hardest pieces of the entire field in psychiatry. This is one of the hardest pointers, and I just want to applaud you for continuing to study and work the problem.

#### **Xavier Amador, Ph.D.** (01:11:54):

Thank you.

#### Ken Duckworth, MD (01:11:55):

I think it's really been valuable. Let's go to the next couple of slides. We have a couple more all stars coming. Marlene Freeman is the director of maternal women's mental health at Mass General Hospital. She is a superstar, and we'll be talking with her about planning for pregnancy when you have a mental health condition, dealing with the risks and benefits of medications when you have a mental health condition, how to think about it before you get pregnant, if you find out you're pregnant, if you are in the postpartum. So Dr. Freeman is a superstar and has led really a lot of the research in this field. Supported employment, this is a way of helping people get a job that Bob Drake and his spouse invented. We'll be doing this with Peggy Swarbrick of New Jersey. Look ahead, we're going to be doing things on long-acting injectables, side effect of antipsychotics. We try to take up the most important things in our topics.

#### (<u>01:13:03</u>):

Next slide, please. NAMI's first book, this is just shameless promotion, I was very fortunate to have Dr. Amador write a brilliant essay on how do you get a person to accept help as part of this book. While I talked to experts across the nation, I also interviewed 130 people, family members and individuals who live with mental health conditions and had them share what they had learned. I was very impressed as I traveled in the field of psychiatry that no one had really asked regular people what they had learned because you, in fact, are also an expert in your own experience. All the royalties go to NAMI. It's a love gift. Let's go to the next slide, please. You are not alone, but this is not medical advice, and of course, you have to integrate this into your own experience. We like donations. There's a little link to donate.

#### (01:14:01):

We have a fabulous team, Katie Harris, Zahira Correa, Alex Dorgan. These teams that provide this support enable us to run these webinars. So thanks to them and thanks to you for donating. Next slide, please. Thanks for joining. If you want to reach out to me, I'm ken@nami.org. It's like a vanity license plate. There's nobody named Ken at NAMI. You can't explain it. Even with the success at the Barbie movie, nobody named Ken has appeared. If you have a question for Ask the Expert on logistics, how to get this recording or the slides, they're all going to be sent to you if you're registered. But feel free to reach out to me if I can be of help to you. Being NAMI's Chief Medical Officer is my dream job, and I consider it a great honor. So again, thank you, Dr. Amador, for this brilliant and comprehensive presentation. Thank you all for attending, and I hope you all have a great evening, and feel free to join us for these future sessions. Take care now.