Navigating Akathisia with Jill Nickens

Episode Description

This week Dr. Drew talks to Jill Nickens. Jill is the president and founder of the Akathisia Alliance for Education and Research. Jill opens up about her personal journey with akathisia, a misunderstood movement disorder characterized by profound restlessness and often misdiagnosed symptoms. Together, Jill and Drew discuss what akathisia entails, common misconceptions surrounding its diagnosis, and crucial signs to watch for if you suspect you or a loved one may be affected.

Transcript

Intro – Dr. Drew: Hey, welcome to the Dr. Drew Podcast everybody. I appreciate you all being here. And please do support us. We want to keep doing this thing. We like doing it. Don't forget to check out “Ask Doctor Drew” that's Tuesday, Wednesday, Thursday typically at 3:00, sign up and subscribe on the Rumble Channel. We would appreciate your support there as well and we tend to move that show around a little bit but I think you’ll find it very interesting, this audience in particular would find it interesting. A lot of folks come in. They've learned a lot by doing that.

Dr. Drew: Speaking of learning something, today will be no exception. Today I'm introducing Jill Nickens. She is the founder of the Akathisia Alliance for Education and Research. AkathisiaAlliance.org is where you can find out more. And although you may never have heard about this topic, it is one of the more important topics for discussion, not the least of which is because, should you or someone you love develop this, you will be misdiagnosed, and you may never be properly diagnosed. And I'm imagining, Jill, that's what's happening to you and your people in the Alliance.

Jill Nickens: It is, and there are actually thousands of people in support groups today, most of whom had or have been misdiagnosed. Akathisia is so horrific that it's nearly impossible not to know you have it even if you don't know what it's called. It's just so unbearable that it can make anyone instantly suicidal. It's that horrific.

Dr. Drew: That is one of the great problems with akathisia. People will hurl themselves off buildings and things because they're so, it's a kind of misery that is rarely experienced. So define, Jill, what it is so people know we're talking about.

Jill Nickens: So, akathisia is a neurological disorder that most often causes severe agitation, an inability to remain still, and an overwhelming sense of terror.

Dr. Drew: And I would argue that you, unfortunately when we start using words like agitation and terror, what happens to people experiencing these things is they get either diagnosed with anxiety disorder and panic or agitation, per se, and akathisia often follows a medication problem. It can be a medication side effect, and so you get diagnosed as tardive dyskinesia, which is a movement disorder, you get diagnosed as having agitation, which is something you may have had before you took the medication in the first place, and now you have tardive dyskinesia on top of that. Tardive dyskinesia, if people don't know, is sort of this, it used to be caused a lot by the major tranquilizers. Now it's less common, but almost any psychotropic medication can cause it where there are sort of mouth movements and leg movements. You see advertising for it now on TV because they're advertising some of the antidotes for it, at least some of the very expensive antidotes that are being advocated. And I bet you're seeing people get put on that all the time too.

Jill Nickens: Well, if there are also signs of dyskinesia, but ordinarily with akathisia, they would start the patient on something like propranolol or a benzodiazepine. But then, if it's not recognized, they'll put the patient on an SSRI or even an atypical antipsychotic like Risperdal or Seroquel that could make the akathisia much worse. And then these people are stuck on all these medications that they then have to taper off of.

And, you mentioned about the terror and agitation being misdiagnosed as anxiety or panic disorder. This is such an important point. Some people with akathisia don't exhibit a movement disorder. I mean, that's been established in the literature for many years; however, most doctors don't know this. So, these people are being misdiagnosed with panic disorder or anxiety, as you said. Otherwise, neurology is misdiagnosing them almost universally with a functional neurological disorder, which basically means that their symptoms are all psychosomatic. Even the people who get akathisia from one IV dose of an antinausea medication in the ER and suddenly want to rip out their IV and run and jump off the roof of the building are being misdiagnosed with these things, and they know it wasn't the sudden onset of anxiety so bad that they had to kill themselves.

Dr. Drew: And, I imagine you saw that more with the Compazine and those earlier drugs. Are you seeing it with Zofran now too?

Jill Nickens: Not so much. I mean, there may be rare cases. But, definitely Compazine, and Reglan is a bad one.

Dr. Drew: Yeah. Reglan causes Parkinson's features too, which is again another kind of quality to akathisia. They look sort of parkinsonian when they're pacing and moving around.

Jill Nickens: Right. I think in one study, 59% of people with akathisia also had drug-induced parkinsonism, so they can show signs of both, and drug-induced parkinsonism is probably also extremely underdiagnosed, at least based on what we've seen in the support groups.

Dr. Drew: This is where it gets so confusing because it often, when it does develop, it's often from a drug or from coming off a drug, so it's confusing and it can be associated with other things like Parkinson's disease or drug-induced parkinsonism, right. And, sorting these things out is so difficult, and this has been my frustration with akathisia, there are not, well, there are treatments, but there are not a lot of good treatments and response is extremely unpredictable.

Jill Nickens: It is. In fact, it varies drastically from person to person. It seems that every time we hear a medication or supplement helped someone, another person says it made them much worse.

Dr. Drew: We really don't fully understand this thing. How about phenobarbital? Have you guys seen much use with that? I've been advocating for that because it fits with sort of how I think things are working. And you might just kind of throw that out and see if anybody gets any benefit from that. And I've had trouble getting patients to take it because oftentimes, well I see it sometimes in acute drug withdrawal where other medications are also being given, so I don't know if it's the drug withdrawal or the medications. That's where it gets so wacky. And, it can be subtle too, right? It can be where people aren't, you know, throwing themselves around or moaning and groaning or pacing around the room. It can be just a feeling of wanting to do that.

Jill Nickens: It can, but again, most doctors don't know this, and the problem is that a lot of the literature refers to akathisia only as a movement disorder. But it's also been documented for many years that it's much more than that. In fact, it's been said that the subjective symptoms, with the severe agitation and the terror, are by far the most dangerous. So, when akathisia is ruled out in a patient only because they're not visibly restless, which happens all the time, this is incorrect and could end in disaster.

Dr. Drew: I worry about calling it, the terror word almost doesn't quite express what people experience, and you would expect that if it were terror, you could sedate it, right? You could give somebody a bunch of benzodiazepine medications, say, and they would get better, but, in my experience, that doesn’t work.

Jill Nickens: Well, you know, it may for some people, maybe even the majority of people, it may work short term, but when the benzo wears off, it's a rebound, right? And actually that's a huge problem, and actually very common.

Dr. Drew: Yeah, you can't keep it going. Yeah, you're worse off. That's why I think phenobarbital might work. Phenobarbital is very different. It's a very different mechanism, and it's much longer acting. I don't know. I keep thinking about that. So, you keep going. You tell me what you want people to know. I feel like I'm confusing people because I guess I'm confused and because it is a confusing syndrome, and mostly I'm mortified that, I've had people with clear akathisia, and getting other doctors to sign on to the diagnosis even is hard let alone finding somebody who knows what they're doing with it.

Jill Nickens: Right. And it's even more tragic because these poor, desperate people have to do their own research. And most of the time, after they figure out it’s akathisia and go to their doctor, the doctor won’t listen. I’ve already mentioned this, but akathisia isn’t subtle. When it happens, you know it. I mean, there's nothing else that could make someone who's not depressed and has everything to live for suddenly over the top suicidal. It's that bad. Now, if every doctor could experience it for even one minute, they would understand.

Dr. Drew: The fact that there are those that have never heard of akathisia is just mind-boggling to me. You know, there's also another – I don’t know if you’re aware of this syndrome, there’s something called tardive akathisia. Are you familiar with that?

Jill Nickens: Yes.

Dr. Drew: And that one gets thrown all over the place because it always, the doctors always want to put it under the rubric of tardive dyskinesia and it's really quite different because that's what happens. The patient comes in with lip smacking or something and then is pacing and bouncing their legs. Well, is that tardive dyskinesia or is that tardive akathisia? Well, I can observe the akathisia. They're pacing around and they're stomping their feet and things and, yes, there is an element of tardive dyskinesia, but we have another thing going on here. I have a patient who I’ve struggled with for 10 years trying to get somebody from neurology to take the akathisia seriously. And I can't get it, it's just not possible. It's really the craziest thing, especially if patient doesn't have resources and things, it's just unbelievable.

Jill Nickens: I know. It’s crazy that so many neurologists have never even heard of akathisia. And, not only are they failing to help these patients, in a lot of cases they're seriously harming them. We had a woman in a support group who was suffering terribly with akathisia. Everyone was rallying around her trying to keep her alive, but she was pinning all of her hopes on a movement disorder specialist she’d found a few hours away. Well, she went to see this specialist and she told her that she had akathisia. This doctor admitted that she knew very little about akathisia, but she disagreed with her and said it was a functional neurological disorder. So, you know, she then became extremely hopeless and defeated. She went home and she killed herself. And sadly, there are many stories like this of, you know, people who thought a neurologist would help them.

Dr. Drew: Yeah, if you ever see video of people, I don't if there are any videos online. Do you guys have videos of people with akathisia?

Jill Nickens: Yes, a lot.

Dr. Drew: Yeah, okay. You should go over there, go to the Akathisia Alliance and check it out because it when you see the distress…. Do you know that thing that's going around, that video of that woman twisting and turning with that sort of dystonia in the streets? To me, that had an element of akathisia in it too. Did you see that?

Jill Nickens: Yes I did. I actually know this woman from an akathisia support group, so she does have it. You're right. And, she also was misdiagnosed by a neurologist with a functional neurological disorder. I know I keep bringing this up, but when people are diagnosed with this or panic disorder or anxiety, they'll be referred to psychiatry. Then the psychiatrist may prescribe a medication that could make it worse, or even increase the dose of the medication that caused the akathisia. Then, if the patient refuses to take it, they can even be court ordered to take it. We actually had a young man in the support group a few years ago who’d been battling akathisia for a long time along with suicidality, but his doctor wouldn't listen or just wouldn't believe him, and he was court ordered to take the medication that caused it. And, you know, we tried to help him. He was trying to think of things he could do to get out of it, but he ultimately couldn't, and he was forced to take this medication. In fact, a nurse came to his home and would sit with him and make sure he swallowed it. And he did get worse. And he did take his life. Just the other day, I read the story of a veteran who had clear signs of akathisia from an SSRI, but he was diagnosed by a neurologist instead with anxiety. He was then put on another SSRI or an atypical antipsychotic, I don’t know which one, and then he took his life because he got worse.

Dr. Drew: And you know what's weird about both those medicines, you know, I've had patients with severe akathisia who get better for periods of time with both, say

Zyprexa and or Prozac, and it seems like a miracle. Fast forward two weeks and it’s all back.

Jill Nickens: Yeah, right, right.

Dr. Drew: It's very odd. Do you, would you be comfortable telling us your story so people understand?

Jill Nickens: Sure. So my akathisia was related to an opioid medication I was put on in 2008 for migraines. I was put on hydrocodone for migraines that I was having a few times a week, they’d tried me on different things, and the next day I was getting this horrible terror and I couldn't stop moving. I was rocking. I didn't know what it was and I went to my doctor. He didn't know what it was. I’d only had to take it maybe twice a week and just one dose would take care of my migraine, but the next day I would get this. I then went to pain management doctor and told him what was happening. He prescribed methadone for me to take daily because he thought this would prevent the rebound symptoms.

Dr. Drew: Oh my God.

Jill Nickens: Yeah. So I went on the methadone and pretty much with my first dose, when my first dose wore off, the akathisia symptoms came back with a vengeance. And then I had where I became tolerant to it and, after about two weeks, it wouldn’t stop. It just didn’t get better. And, then it was a series of on and off something called buprenorphine which is, you know, an opioid.

Dr. Drew: Yeah, I'm curious how that worked. That's an interesting move.

Jill Nickens: When I went to a doctor, he just knew it had something to do with opioid withdrawal. Now I'd been without one for about two months at that point, and I was still having terrible symptoms. He gave me one dose of buprenorphine in his office, and I sat there and within 2 minutes it was gone.

Dr. Drew: So that's interesting, right?

Jill Nickens: Yeah. And there are a few studies, maybe in the 70’s, of opioids helping akathisia.

Dr. Drew: Well, but buprenorphine is what's called a Kappa opioid agonist and it has very unique properties and it does imply, I wondered if the Kappa system was involved. That's why you caught my attention. You said he gave you buprenorphine and I thought, oh, I bet that's going to work. Now, it could be a problem because it also has mu opioid effects as well.

Jill Nickens: Right. Well, I believe I was becoming a bit tolerant to my dose. I can't honestly remember if I had to increase it. This sounds kind of dumb, but about three times I forgot to take it or misplaced it, and then I would end up with just horrible

symptoms. I'd get lost when I was driving in my own neighborhood, and three times I ended up in a hospital. The last time it was life threatening. And, so, there's a lot of mistreatment in the hospitals because no one believes you, especially when you add the fact that the medication I got it from was an opioid. So now I've got, “is she faking symptoms for attention?” or is she...

Dr. Drew: ...a drug addict trying to get drugs? Oh boy.

Jill Nickens: Yeah. So that's what started my saga. That's why I spent so much time researching and that's why I've done all of this.

Dr. Drew: And so how are you controlling your symptoms now?

Jill Nickens: Well, I don't take any medications to control them, but at least I don't have the severe movement disorder aspect with the constant pacing anymore. I'm very fidgety and I have some parkinsonian symptoms, and I still have a lot of the subjective symptoms, especially the sense of terror that's pretty unbearable most of the time. I basically just distract myself, mostly with work.

Dr. Drew: That sounds unpleasant.

Jill Nickens: A little bit. And, you know the problem is I'm highly functional now, so people don't understand that there's anything wrong with me. You know, why I can't do some things.

Dr. Drew: Does your brain not only adjust to it in the sense that it kind of gets better, but do you, I don't know of any other way to say this, find a way to live with it, you know the way people live with chronic PTSD symptoms or grief or things like that, they kind of, their brain can adjust a little bit to living with it.

Jill Nickens: Well, I suppose if you're one of the unlucky ones and it doesn't completely resolve, then you can somewhat learn to live with it. However, there will be triggers, definite triggers and very bad days and very bad times when you'll think you just don't want to do it anymore.

Dr. Drew: Are there physicians out there or resources that people who suspect they might be dealing with something like this can go to other than the Alliance. I mean, do you have stuff specifically there? And what do you have?

Jill Nickens: Yes, there are a lot of resources available on our website. We have a guide for family and friends. We have a guide for clinicians. We also have a new flyer people can print out. It has basic information about akathisia as well as information specifically for clinicians about the reasons it's misdiagnosed that will hopefully help more people get a diagnosis.

There are also pages on our website specifically for patients, one for family and friends, one for clinicians, because educating yourself and educating your family

and educating your doctor is the most important thing because it's so misunderstood. There's also a resources page that lists some of the support groups and other websites people can visit.

As far as doctors, unfortunately I don't think there are a lot, but thankfully word about akathisia is spreading very quickly now and it seems that more doctors are coming on board and willing to help these patients. Of course, it's a hit or miss. What I would say is to start with a movement disorder specialist. I would definitely encourage these people, though, to take the new flyer that we have on our website to that movement disorder specialist because it was designed specifically to overcome the reasons we're being misdiagnosed. Otherwise, I know of a few experts who've been studying akathisia for many years. One is Perminder Sachdev from Australia and Stewart Factor, and just a few others.

Dr. Drew: I had a conversation with Doctor Lieberman. What is it? Jonathan Lieberman. He was the former chairman of the American Psychiatric Association, or was the head of that organization, and he seemed very knowledgeable. In fact, we were working on a case together and he was he was breaking down to different types of akathisia which I'd never really heard of. I'd heard of tardive akathisia, but he was like, you know, I forget even how he was doing it in terms of the motor activity that he was seeing. I should look him up. He has a book called "Shrink," which is kind of the, it's about the catastrophe of the history of American psychiatry, which is not great. And, you alluded to it a little bit in the beginning of this conversation which is that the psychoanalysts had such a profound hold on the first half of the 20th century that we couldn't do any medicine, they were doing psychoanalysis all the time, which is a nice, interesting philosophical foray into the human experience, but it has no clinical utility, limited clinical utility, and certainly no utility in a neurological disorder or maybe helping manage the symptoms, you know how you live with it. Well, it's really interesting. Are you hopeful for the future? Are you aware of any medication coming down the pike or research that's being done?

Jill Nickens: Well, unfortunately I'm not aware of any medications coming out, and certainly people with akathisia are very hesitant to take another medication, and I'm not actually aware of any research that's being done, but I'm becoming more and more hopeful for the future because, well, because of people like you who care and are helping to give us a voice. At least this is a good first step. Now once everyone learns about akathisia and how many suicides and acts of violence it's causing, hopefully research will get started and maybe treatments will be discovered. Actually, if there are any researchers listening, we have a patient registry with over 700 people who've had akathisia. They've been screened regarding the medication that caused it, as well as their symptoms, so there are over 700 cases that could be published, including many suicides.

Dr. Drew: You know, I had this tremendous clinical experience when I was a workaholic, where I was working, you know 10 hours in a psychiatric hospital and 10 hours a day in a medical hospital. And yeah, it was nuts. That sort of hypomania. And so I saw everything, everything, everything and I've seen all this stuff, so I'm acutely aware of these syndromes that caused this tremendous distress to patients that need very specialized and focused care, and very few people seem to be getting it because most doctors never see these things or if they see it, they're unaware they're seeing it because they've not had the breadth of experience that, some of the doctors are so narrow these days in what they're seeing and this is disturbing to me. It reminds me of the sexual dysfunction and issues we're seeing with SSRI's, which is in many cases permanent, and I think most people know that it can, you know, drive libido down and things when you're on the medication. But most people, I would say vast majority of people and vast majority of doctors, are not aware that there's this permanent syndrome and literally 10s of thousands of people are affected by it, and no one's kind of listening, and that that drives me crazy. And this akathisia is the same thing. And you know, I've taken care of some high-profile people who have had this too. And, thank God it's lifted, but I wish they would talk about it because that would help sort of bring the awareness of how incredibly miserable this is. And you keep using the word terror. And I know that's your experience, and I don't want to in any way question that, but the one thing that I see as somebody trying to understand what a patients experience, the thing that comes across is misery, misery, misery, misery and is that because of the terror, or is that a separate phenomenon, do you think?

Jill Nickens: Well, I think it's the combination. But even one of these symptoms, whether it's the agitation or the terror or the constant need to be moving at all times, you know, each of those is miserable enough, but when you put them together, it's a nightmare. It's unbearable.

Now, the terror would be a very difficult concept to grasp if you haven't had akathisia. It's like you're sleeping and having a horrible nightmare. So you're actually experiencing this event, or living in this event in your head. You weren't just worried that it was going to happen like anxiety. It's not that. It's as if it's literally happening to you at the moment. And, when you wake up suddenly and absolutely terrified, it's that feeling. And it just never goes away. It's that feeling.

Dr. Drew: But see, that sounds like panic though, right?

Jill Nickens: It does, and there may be something similar in their pathophysiologies. It seems that way because a lot of people have said akathisia is like having a permanent panic attack for no reason.

Dr. Drew: And, people with panic can get these agitated states that kind of look a little like akathisia, which is why they get misdiagnosed all the time. It's this weird zone that, if we just had some way of, you know, figuring out the pathways in the

brain so we could maybe light them up and, you know, check them on a PET scan or something. You know, I have little confidence that we're going to get there in the near term, not just because it's sort of science fictiony, but everyone's biology is so different with this thing.

Jill Nickens: It is, certainly in the sense of which medications cause the akathisia and whether it occurred when starting the medication or stopping, but this is one of the main reasons we started the Alliance. You know, each doctor may see a patient with akathisia here or there. So, having only a handful of patients to draw similarities or to study can't be very effective. Now, if you get hundreds or even thousands of people who've experienced akathisia together, such as in our patient registry, then it's obviously much easier. We've actually done some research to help better define the symptoms of akathisia. We targeted people who got it from just one dose of a medication. What we found is that in addition to the restlessness, the agitation and the terror, most people also have rapid speech, agoraphobia, monophobia or difficulty being alone, hypersensitivity to light and sound, insomnia, depersonalization-derealization, which is a sense that you're detached from your body or your from your surroundings, and there are a few others. And, almost everyone who got akathisia from one dose of an antinausea medication had the same symptoms.

Dr. Drew: Are there any other antecedent symptoms that you can identify so people can know that they should be being careful? You mentioned a family of Parkinson's. Are you finding that?

Jill Nickens: Yes, Parkinson's or family history of Parkinson's. ADHD is another big one. In fact, it was very easy for me to draw similarities between akathisia and ADHD because each of the four times I went cold turkey off an opioid, in my head it felt like I was sitting in a car watching the scenery go by at, you know, 20 miles an hour, and then suddenly when the akathisia hit, it was like the scenery was going by at 100 or 200 miles per hour.

Dr. Drew: That's interesting. Are there other things you want people to know about akathisia or what they can do or where they can go or how they can get support or what? I guess, maybe frame it this way for starters, if somebody is a family member or friend of somebody with this thing, what can we, it's a very helpless feeling being around somebody with this condition, what should we do?

Jill Nickens: This is so important. As we've seen time and time again, when people with akathisia lose the support of their family, they're much less likely to survive. And sadly, if they do lose support, it usually begins with a doctor who didn't recognize or diagnose akathisia. So when they tell the family it's just anxiety, the family thinks they can overcome it with more medications that the person knows they shouldn't take, or with yoga or positive thinking, but those things aren't going to help this chemical nightmare in their head that's making them suicidal. But the

family doesn't understand this. So, when these people don't follow their doctor's instructions and don't do yoga or take the medication the doctor wants them to take, the family gets angry with this person for acting like they know more than their doctor about what's best for them. Now, what these family members don't understand is that they can't afford to do anything that might make them worse, because, like the majority of people with akathisia, they're very likely already on the verge of suicide whether or not they'll admit it. In many cases, people had admitted it in the past and then been involuntarily hospitalized or even force-drugged with the medication that caused the akathisia. So, at this point, they can't admit it anymore, and they can't call 911 when they're feeling suicidal, as people are told to do. On top of this, if the family is hard on them, if they stop speaking to them or even sometimes kick them out of the house, they may feel they have only one option. This honestly contributed to the majority of the suicides we've had in the support groups, so I can't emphasize this enough. The most important thing is to believe this person and stay by their side regardless of what their doctor tells you.

I have a true story that's an example of how misdiagnosis can lead to abandonment and ultimately suicide. A few years ago, I received a video of a woman who was an attorney in her late 30's who'd had to move back into her parents' home because she couldn't work. She'd been misdiagnosed with anxiety rather than akathisia, so no one believed how sick she really was. Her mother was obviously extremely frustrated with this and, in the video, she was screaming at her daughter to take her things and get out of the house. And, the last thing the mother yelled at her was, "All of your caregivers say you can do better!" Of course, these caregivers didn't know she had akathisia, and this woman took her life that night. Another woman in the akathisia support group posted that she couldn't get her doctor or family to believe she had it. She said her family was getting very angry with her. In her final post, she said that her father told her to go ahead and kill herself because she was hurting them with her "delusions and invented diseases." We heard she'd taken her life a few days later.

Dr. Drew: It's such a weird, it sounds heartless for a family member to say that. And, of course, the outcome was the worst possible, but I can sympathize with their feelings because you feel so out of control and the symptoms are so in your face. I was thinking about a woman I had who had opiate withdrawal syndrome similar to yours, but her primary external manifestation was uncontrolled sobbing but sobbing in a way that she was throwing her arms around and stuff, and it's difficult to be around that, right? By the same token you said that people get constrained. That's why they get constrained. But I have, you know, constraint is a very bad, you know it's and evil word right now, but I I've had family members hire security guards to constrain akathisia patients so they don't throw themselves out of the car or don't throw themselves off a building like when they get, when they start hurling themselves, they will throw themselves into the wall and the furniture and things like that. And somebody holds them, and it's not a pleasant experience for the

patient. It's not like they feel better when they're constrained like, in some psychiatric conditions people feel better when they're constrained. This is not one of those conditions, but they don't kill themselves or hurt themselves. So what do we do with that?

Jill Nickens: Oh, right. Well, obviously the most important thing would be to keep the person safe. But if they do need to be restrained, at that point letting them know they're safe, we're not going to…

Dr. Drew: Yes, yes that definitely is the general note. I agree with you. I know that when I see this in relation to drug withdrawal, I usually have a sense that it's going to pass and it usually does. I don't mean drug withdrawal in the sense like part of the withdrawal syndrome. It's not the primary symptom of withdrawal. It's just part of what went haywire in withdrawal. And in that situation, and it's usually a benzodiazepine because people get given a lot of nonsense medication in that withdrawal, that it usually will pass and it usually does. So, that's always been my approach and that's what I often see. It's like, "Is this is going to get better?" and there's a lot of "I can't, I don't know if I can…".

Jill Nickens: Yeah. Right. It's really sad, but in the support groups, it's constant people posting, "I can't do this anymore" and everyone's banding together and trying to help that person survive. And it's almost like a roll call every day, "Is everyone present today?" It's just, no one could believe it who hasn't experienced it.

Dr. Drew: I agree with you. It one of the worst. It's why I was so anxious to talk to you because it's one of the worst conditions I know of. It is torture. We've talked about terror. We've talked about dread. We've talked about misery. But, the other symptom that people complain a lot about or express is desperation. The reason it jumped out for me so vividly is that's what opiate addicts always experience in withdrawal, and no one ever talks about the desperation they feel. They just they see them as wanting to do drugs, but they want to do drugs to relieve the desperation. And they know the drugs will relieve the desperation in the setting of opiate addiction. In this setting, not so much.

Jill Nickens: Well, I can't personally differentiate between the two because I got akathisia from opioid withdrawal, but the symptoms are so awful when they hit that you have to make it stop immediately. An analogy I've heard regarding the desperation is to imagine you've been lit on fire, so you're literally on fire. You then beg your doctors, your family, and your friends for a bucket of water to put out the flames over and over and over, but they can't see them, so they don't believe you. Then their doctor tells them that you're not really on fire. And finally, one by one, they turn their backs on you. This makes the desperation much worse. Actually, in addition to their family and friends, people with akathisia often lose their job, their home, and sometimes even custody of their children until they finally have nothing

left to live for. But, most people with akathisia are desperate because they don't want to die, they just need the torture to stop.

Dr. Drew: So take me through this again for clarification purposes because I started out as a bit of a Rorschach because I'm so frustrated with this condition and my peers. Take people through this again. What kinds of misdiagnoses, what are the common misdiagnoses that people should look out for?

Jill Nickens: Well, most often severe anxiety, panic disorder, and then they may try to fit them in other boxes of a personality disorder. And then there's agitated depression, psychomotor agitation. There's also the functional neurological disorder, as I mentioned, conversion disorder and somatic symptom disorder, which basically mean the same thing. And another one we can get is health anxiety, which is like you're a hypochondriac because we'll visit several doctors and we keep insisting there's something terribly wrong, but they're not seeing it. Then we also appear to be obsessed with research. I've also heard of people being misdiagnosed with factitious disorder, which basically means that they were faking symptoms for attention. And then the people who get akathisia from drug withdrawal can be diagnosed with drug seeking, which they're technically doing, but they're not doing it to get high. They just desperately need the drug to stop the akathisia. Actually, a lot of people who take a benzodiazepine like Xanax exactly as prescribed get akathisia if they run out of it, or even when they become tolerant to their dose. When this happens, they're not asking the doctor for the benzo to get high, they just need it to make their akathisia stop.

I was actually in an emergency room one time when a man came in who was extremely agitated and pretty out of control. He was restrained and the police were called to be at his bedside. He kept yelling over and over that he just needed his Xanax. It was pretty obvious to me that he had akathisia and that the Xanax would have fixed the problem, but they wouldn't give it to him. And the scary thing is that people like him can be injected with an antipsychotic, which could make the akathisia a lot worse. This would basically be torturing them when all they would have to do is just resume the benzodiazepine at their normal dose and they'd be fine.

Dr. Drew: I understand you are, I don't know if it's your group or you, but some have expressed a theoretical concern that akathisia may explain some of the mass shootings that have been linked to the use of psychotropic medication.

Jill Nickens: Yes. Well, it's been reported that most of the mass shooters had been taking a psychotropic medication at some point before the shooting. But, since millions of people take these medications who don't become homicidal, this is only correlation. On the other hand, it's been known that akathisia can cause homicidal behavior since the first of many cases was published in the 1970's. So, if it can be

proven that a mass shooter actually had drug-induced akathisia at the time of the shooting, then it can, in a sense, be said that the psychotropic medication caused it.

We have a video called the “Missing Link to Causation,” and we'll have a report coming out soon with the same name. They both feature high-profile cases of mass shootings or homicides that may have been due to drug-induced akathisia. The report contains evidence that the Sandy Hook Elementary School shooter may have had akathisia for years before the shooting. Another case featured is that of an ex-NFL football player named Phillip Adams who shot and killed his doctor, the doctor's wife, two of his grandchildren, and two men who were working at his home. It was reported that the doctor had recently stopped giving Phillip a medication and it was suspected that this was a possible motive. Now the type of medication wasn't disclosed, but there is a good chance it was an opioid since Phillip had sustained many injuries during his football career.

Although a connection wasn't made at the time, Phillip’s family said that he had recently become very aggressive and angry, showed unusual behavior that they hadn't seen before, and it was very concerning to them. Then, Phillip's neighbor said that he had seen him pacing aimlessly out in the field for many hours every day in the months before the killings. And while this isn't definitive evidence, these are all signs of akathisia, especially the pacing constantly is a hallmark sign.

Dr. Drew: And it's a certain kind of pacing too. It's not, it's not a usual gait. You're not swinging your arms, and you know, trucking along. It's almost parkinsonian sometimes, but it's not as narrow. It's not as shuffling.

Jill Nickens: Right. Yeah. And the really sad thing about that too is the need to pace for so many people is so strong that people, I had a friend who had very bad knees and people who have bad hips or bleeding feet. They have to pace anyway. It's just miserable.

Dr. Drew: I'm looking at akathisiaalliance.org. This website has got a lot of great, just this opening page I think I'm on. There’s just tons of stuff here that’s a really good primer to get started if you have concerns or concerns about a family member. It's sort of a 2-sheet. It doesn’t mean you have akathisia, but you've got to get doctors to think about akathisia with these syndromes because it's dangerous, and it could get a lot worse if you're not careful about what you're exposed to, and it certainly is going to get better. But you know, I always tell, when I was training residents saying, “no diagnosis, no treatment.” You do not give a treatment without a diagnosis, you could only do harm. That way you don't even actually know what you're doing. You're certainly not going to get benefit, so make sure you get properly diagnosed. Is there anything else you want people to know about this before we kind of wrap up?

Jill Nickens: Yes, it's important for everyone to learn about akathisia because it can be caused by hundreds of medications, including things like antibiotics, and it can

make anyone instantly suicidal. But there's a good chance your doctor has never heard of it. There's also a lot of misinformation in the medical journals. For example, a recently published paper claims there's no reliable evidence that akathisia can cause suicide, but we've lost over 100 people in one akathisia support group to suicide since 2018. These cases aren't being published, so doctors don't realize how many people are dying and why this is an emergency. There are also thousands of people in support groups today who are on the verge of suicide, and they desperately need help.

Dr. Drew: And, the first way we're going to do that is with understanding and identifying the issue. So, do check out akathisiaalliance.org. Check it out. It's a simple read. There’s like a two-page flyer you can print it up right? Is that how it's designed? It looks that way.

Jill Nickens: Yes, and you can print it right from the home page, and it's also in our “Educational Materials” page as well as the “For Clinicians” section. Now, this flyer has general information about akathisia as well as some specific information for clinicians and neurologists. Honestly, if there are people listening who have akathisia and still can't get a diagnosis, I would say take this this flyer to a neurologist.

Dr. Drew: Take it in. Yeah. That's why I was saying print it up. I 100% agree with you. It, it would not be offensive to a physician. Just go, “Hey, I was reading about this. And look, I have all this.” Wonderment is an incredibly effective tool for everybody, no matter which side of the clinical table you're on, the patient side or the physician side. So please take advantage of that. Jill, it's been a pleasure talking to you. I'm sorry you still have symptoms with this. I wish there was something magical we could wave over you because I do, I do get it. It's one of the things that I would just dread having. And, there's lots of things out there humans can get and this is one of them. And also I imagine you want people to go to the support groups if they have any questions or concerns.

Jill Nickens: Yes, there's a wonderful one on Facebook called “Living with Akathisia” and there’s....

Dr. Drew: Do you have to be formally diagnosed? Or, if you're wondering if you have it?

Jill Nickens: Oh no, not at all. By the time people get there, that means they’ve done enough research to have learned the word….

Dr. Drew: At least they're in frustration mode. Is there a website you want people to go to for you, or is it just the Alliance where you want them to go?

Jill Nickens: Well, just akathisiaalliance.org, but also if there are any researchers listening who are interested in akathisia, please contact us at research@akathisiaalliance.org.

Dr. Drew: Alright, Jill, thank you so much. And for everyone else, we'll see you next time.