

NAMI Ask the Expert:
Movement Disorders as a Side Effect of Psychiatric Medications

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Featuring: *Craig Chepke, MD, DFAPA*

Dr. Ken Duckworth (00:00:00):

Thanks to our entire team at NAMI who produces these fabulous and free Ask the Experts. One of these we're trying to do in this webinar was attend to movement disorders, which I think are overall underappreciated, underdiagnosed and maybe the average community psychiatrist doesn't have the expertise that we might like. We had tried to do side effects two months consecutively. Due to the nature of our expert schedule we're going to be doing metabolic side effects, weight gain, diabetes, the role of compounds like Ozempic in November, so again, it's a two-part series on side effects of antipsychotics. We know these compounds have side effects, we want to empower people with the best information possible. All right, let's go to the next slide please.

(00:00:55): You know about the NAMI helpline, 1-800-950-NAMI. Trained people are there to support you and to send you in the direction that might be helpful. This is not a suicide prevention lifeline, but is a very valuable resource for our community. Next slide, please, Katie. Our speaker today is fantastic and in addition to being an Exemplary Psychiatrist Award winner, a Duke residency graduate, and the scientific director of Psychiatric Congress, he also is doing this Ask the Expert from Tokyo today. He happens to be in Tokyo for a major psychiatric meeting and as a true gentleman, he elected to not cancel on us knowing that he would be in Tokyo, but rather to get up at 4:00 in the morning.

(00:01:46): Craig Chepke is an expert on many things in the serious mental illness space. We're calling upon him specifically for his expertise in movement disorders, so with that I want to say welcome Dr. Craig Chepke. Thank you so much for our first international presentation from the other side of the biggest pond, not England, so take it away and I'll be back for your questions, which I'll be sorting and giving to Dr. Chepke. A number of you sent questions in advance. Brilliant. Keep them coming during this conversation. We'll try to get to as many of them as humanly possible. Thank you.

Dr. Craig Chepke (00:02:28):

Well, thank you very much for that introduction, Ken. I appreciate it, and yes, I am here in Tokyo live and I'm excited to be here. I wouldn't be anywhere else but be able to give this education to everyone who logged in this morning. Medication-induced movement disorders has been a passion of mine for a number of years and I want to increase that knowledge and as Ken said, empower people out there to understand them better and what to do if you think you may be experiencing one. My outline of the presentation, there are... Gosh, actually at the residency program that I do teaching for, I actually teach a six-hour course on drug-induced movement disorders, so there's no way I could ever get through the entire breadth of the topic today and even the six hours is abbreviated, so I'm going to cover some of the most common ones, tremor and then ones that you may not have heard of before. Akathisia, dystonia, drug-induced Parkinsonism and tardive dyskinesia.

Dr. Craig Chepke ([00:03:23](#)):

Tardive dyskinesia is where I want to spend the bulk of the time, but I do want to build to that one. And for each one of these topics, I broke it down into some specific sub-bullets. What is it? When is it likely to occur? What can it look like? What might cause it? How common is it? Who is more at risk for developing it, and then what can be done about it? And one thing I want to say in general before we get started is that there's so much information in this topic that it was hard to really slim down, so the slides are going to have a lot of information on them, but I knew that you would have access to them after the presentation and therefore I elected to leave more information on the slides and I'm going to cover less during the presentation because you'll have access to the slides as a resource that you can go back and look at some of the finer-grained details after the fact.

([00:04:12](#)): And I'm going to click through a lot of them, especially early on a little bit faster, but then also can clearly address things during Q&A as well if you have questions that something that was set on a slide but that I didn't actually verbally cover. Briefly there's two different ways we categorize involuntary movements in movement disorders. There's hypokinetic and hyperkinetic, so hypo meaning less, hyper meaning too much. Really the bulk of movement disorders are hyperkinetic as you can see from the size of the bucket, the number of names in it. Hypokinetic is really Parkinsonism and most people are familiar with Parkinson as the Parkinson's disease, but there is Parkinsonism, a greater category of hypokinetic movements which may or may not be related to the actual Parkinson's disease and can be medication-induced and can be things that are not Parkinson's disease but not medication-induced either.

([00:05:12](#)): We're not going to go into all of that and many of the different hyperkinetic movements we're not going to go into as well. Things like apoptosis, ballism, it's a little bit too complex for today and I can try and keep it simple, but I wanted to keep you a broad overview at first. I'll go ahead and build this out. This is what it would look like to do a really full classification of everything, so the point of this was just to show you this is complicated, and as Ken said, the average psychiatrist or other psychiatric provider in the community, we didn't get trained on this. And so if you're experiencing what you believe might be a movement disorder or medication-related movement disorder, your psychiatric provider may or may not be able to give you this level of detail.

([00:05:59](#)): Now, the average psychiatric provider, I think we should expect to have some level of knowledge of movement disorders that are caused by psychiatric medications. It's our responsibility to be aware of at least the basics of every side effect of every medication that we are prescribing, but sometimes it might get a little bit beyond what the average psychiatrist or other psych provider can be able to manage themselves, which is why we have colleagues in neurology and specifically movement disorder neurology that can help us out if it gets overly complicated.

([00:06:33](#)): One thing I did want to point out though is that with Parkinsonism, it's kind of a hybrid between the two because predominantly Parkinsonism is when there's too little movements, but if you've ever met a person living with Parkinson's disease, then you probably noticed that many of them do have tremor, and so that bridges the gap between the two worlds, but still predominantly it's a hypokinetic movement disorder. Tremor is very common and this is one that... Ken mentioned we're going to mostly focus on antipsychotics, but there are a lot of medication-induced tremors that are not antipsychotic related. Antipsychotics can themselves cause tremor, but there are many other medications that can cause tremor as well. Lithium valproate or valproic acid is another common one. I tend to use the generic names for medications.

Dr. Craig Chepke (00:07:23):

The brand name for valproate or valproic acid would be DEPAKOTE or related ones. The antipsychotics I mentioned, antidepressants as well and caffeine. Caffeine can... One way of looking at it is cause of movement disorder, it's really just enhancing the body's natural tremor, but I got a chance to look at the questions that were submitted from registration and there were phenomenal questions already before I even got started. I'm really excited to get to QA and one question that I want to go ahead and address now is can caffeine worsen movement disorders? The answer is yes. Caffeine can worsen or bring out one that may not have been notable before, so if someone's struggling with a movement disorder, reducing caffeine intake is one way that they can work on trying to improve that. But a tremor importantly is something that is very rhythmic, so if I was to mimic a lithium tremor, normally would look something like this. If I slow it down and exaggerate it for educational purposes, it's the same thing over and over.

(00:08:24): Tick, tock, tick, tock, tick, tock, same thing over and over again like a video that is on a loop. That's what is characteristic of a tremor. Other movement disorders that are not tremor don't have that same perfect rhythmic nature, so in order for it to be a drug-induced movement disorder, we want to rule out does the person have Parkinson's disease? What's called essential tremor, it's a tremor that is familial and is passed down in the family genetically. Low blood sugar, hyperthyroidism and many other medical causes can be the result of tremors as well, but if it's due to a medication, it should start pretty closely immediately.

(00:09:03): Some of the mood stabilizers like lithium, anticonvulsants, which include valproate, can add fairly high rates of the tremor and the risk of developing it as people get older. As they're on multiple medications, the risk of having medication-induced tremor goes up. Now we're going to focus on ones that are predominantly associated with antipsychotics, dystonia, and for all of these ones I have a little diagram off to the left and where it's highlighted in the deeper shade of color is where it's more common to happen. For dystonia along the spine and the shoulders, in the back, the shoulder in the front as well, the tongue and the eyes. Dystonia is a sustained movement disorder, so whereas the tremor was like this, with dystonia it's that the movement is sustained. If it's in the shoulder it could be one side is pulled up where the muscle's contracted and it stays contracted and this is someone that occurs very quickly.

(00:09:59): About half of the cases occur within the first two days and 90% within five days of starting an antipsychotic, so if this is going to happen to someone, it happens almost always in the first week. It happens very quickly. Dystonia is often a painful one because if you can imagine if you try to keep your muscles contracted like I was showing you, eventually that's going to start to hurt. It's something that usually is noticeable visibly and it's usually twisting as well in the arm. It will often will rotate it out or inward this way instead of being that. It rotates things is the nature of a dystonic movement. In terms of how common is it, older first-generation Antipsychotic, the typical antipsychotics, 10%. Less than 2% probably with the newer medications. And who's more at risk are people with bigger muscles is one way to break it down.

(00:10:56): Younger people and those who have greater musculature are at greater risk because of the more muscles they have and it goes down with time, so just as most people over time will have some loss of muscle tone in general, then it tends to go down and there's almost no risk over 45 years old. But what to do about it? Well, it can be alleviated with what we call anticholinergic medications. Now, there's a number of different things that can fall into that category. The most common one is called benztropine. Cogentin is the old branding for that, or diphenhydramine, BENADRYL. If someone has acute dystonia within the first couple of days, usually if it... As I said it's painful, they may go to either primary care or emergency department and they'll get an injection of something like benztropine or diphenhydramine.

Dr. Craig Chepke (00:11:46): Now, this is something that you really shouldn't need long-term treatment for if it's medication-related. There are non-medication related dystonias that are long-lasting, permanent so to speak, that are specific disorders in and of themselves. That's different, but if it's medication induced, then we should change the medication that causes it and we are able to do that in most cases. And also slowing down the dose increases. If someone's dose is being rocketed upward, that increases the risk and so we can slow it down, but someone really shouldn't be on one of these anticholinergic medications like benztropine, Cogentin or diphenhydramine, BENADRYL long-term for this. It has oral medication as well.

(00:12:29): Now, because it is a much greater risk with the first generation of antipsychotics when those were the mainstay of treatment, they're still used in some cases today, but before the second generation antipsychotic [inaudible 00:12:41] all we had because it is often painful and uncomfortable, then it was something that clinicians, psychiatrists didn't want their patients to experience because they thought, "My goodness, they'll never take the antipsychotic if they are experiencing this. Why don't I just start them on this anticholinergic ahead of time? Before they ever get we use it to prevent the dystonia." And at the time sounded like a good idea, but it became so widespread that it became problematic especially because as I mentioned, the 90% cases were within five days and so there's really no need to use a preventative treatment of more than a week at most.

(00:13:20): But unfortunately people to this day have been put on preventative prophylactic, benztropine is the most common one, Cogentin is most common preventative anticholinergic, and stay on them for years or decades even when they're completely unnecessary. This is against World Health Organization recommendations and there's only a very few specific cases these days in which they should be used preventatively, and I listed in there someone who had dystonia in the past. Clearly that one makes sense. A young male with no antipsychotic exposure in the past and recent cocaine use, getting pretty specific. And then if someone requires rapid dose escalation of that first generation of antipsychotic and they have to be secluded because they are a violent or dangerous, for some reason they can't be around other people for the safety of others, these are the only reasons that it should be used preventatively for the guidelines, but it's still used very common.

(00:14:13): And the problem with these anticholinergic medications is they have a lot of side effects of their own and we really shouldn't be putting people on those for long term because they're unnecessary. Now, akathisia is the next one and this is a sense of restlessness. Now people with anxiety can feel restless at times or appear restless, people with ADHD can feel restless, but this is different. Someone with ADHD, if you ask them do you feel restless most of the time will say, "No, I feel fine," even if they're moving all over the place, bouncing off the walls so to speak. But with akathisia they feel restless like ants in their pants, their skin's on fire are ways that people have described it and it's very uncomfortable and they feel like if they can just move the right way that it will alleviate that, but there's no way they can move in order to get it to be alleviated, and it's generally in the lower half of the body.

(00:15:07): It can be sometimes confused with restless leg syndrome. That's something that again, the average person in the general population has never heard this term akathisia, so if they are experiencing as a result of the antipsychotic treatment, then they may say, "I feel like I have restless leg syndrome," because that's something that many people have heard of. It's again likely to occur very, early 75% within a week, and we don't understand what causes it as much as we do some of the other movement disorders. It can be highly variable within both first and second generation antipsychotics. There's wide variability of ones that are very unlikely to cause it or ones that are very likely to cause it and everything in between, and we don't have good risk factors as to who is more likely to develop it like we do with some of the other movement disorders.

Dr. Craig Chepke (00:15:55): And what can be done, this one is very commonly associated with how quickly medication's being started. I liken it to with driving. If you're in a sports car and you hit the gas from the stop position, it blows you back with the inertia, but then if you can get up to going a steady speed of 70 miles an hour, heck, 100 miles an hour and you don't even feel like you're moving and that's what is often the case for akathisia. If the dose is increased too quickly, then the person may get akathisia, but if the dose is increased more slowly, then it's much better. And then once they get to a steady medication dose, it often can go away completely, so if someone experiences it, what I will most often do is lower the dosage that I was trying to increase, bring it back down to a lower starting dose, cut it in half or something like that, and then go up more slowly and then use other medications to treat the symptoms until the symptoms go away while we're doing this.

(00:16:54): Something called... Well, there's medication called Propranolol, which is... The class of it is a beta blocker and these are used and FDA approved for high blood pressure commonly, but they also help with akathisia. Another antidepressant called mirtazapine is shown to benefit it. In really severe cases, Clonazepam can be used. It's a controlled substance and it's something that we would not want to use for long periods of time because controlled substances have risks of dependence on them, but most commonly, as I said, the best thing to do, just slow it down and titrate more slowly. And then there are antipsychotics listed at the bottom down here that are much less likely to cause it in terms of the... They may have other problems like Quetiapine. It can also cause a lot of sedation and weight gain and things like cholesterol, and blood sugar increases might be a reason not to use that.

(00:17:54): And then some of the newer ones, brexpiprazole, lumeteparone, very low risk for other adverse effects as well. Clozapine is one of my favorite medications for many reasons, but it also has some potential drawbacks as well. Now, drug-induced Parkinsonism, that's an actual road sign I saw one time that I was able to find a clip art of, a slowdown dip means a dip in the road, but DIP is our abbreviation for drug-induced Parkinsonism. Now, I mentioned earlier that the predominant aspect of Parkinsonism is the slowness and stiffness of the muscles, and if you have ever met or have someone in your family with Parkinson's disease, you've seen this. It's that they move slowly, stiffly. Well, sitting here it's hard to do the movements that I generally try to mimic, but they don't swing their arms, they take short shuffling steps, things of that nature. And sometimes they do have a tremor.

(00:18:54): Tremors are actually even more common in Parkinson's disease than they are in drug-induced Parkinsonism, so if we're only looking for tremor to diagnose drug-induced Parkinsonism for the clinicians out there, then we're going to miss many of the cases. It's really the slowness and the stiffness of the movements that are the hallmark of drug-induced Parkinsonism, but it's a generalized slowing. It can slow down their cognition, it can slow down their mood, their affect. Then people may say that they are feeling depressed when they are experiencing drug-induced Parkinsonism because it comes on slowly comparatively to the other ones that I've mentioned today. Half of cases occur within 30 days and then 90% within 72 days. That's still quite a while that it might be slow and insidious and may not be noticed as opposed to the other ones which are more abrupt. Now, it's more common in the... This is again widely variable depending on which medication it is, but pretty high numbers, 15% up to 31%, up to one out of three people on antipsychotics.

Dr. Craig Chepke (00:19:56): The higher numbers are generally the older first generation antipsychotics, but even some of the newer generation antipsychotics can have a decent high risk of drug-induced Parkinsonism. In this one, there's a very clear risk factor increase in age. As the brain and nervous system ages, it becomes less capable of dealing with the Parkinsonism from the antipsychotics overall. And if someone does develop tremor, it's in those darker green shaded areas on the lower left, so in the neck, the jaw area most commonly, in the wrists and hands. It's called a pill-rolling tremor is the classic one that we tend to talk about with Parkinson's disease and drug-induced Parkinsonism and then in the feet as well.

(00:20:44): What can we do about this one? Again, change it to a medication that is less likely to cause it. This is predominantly related to how tightly it binds the dopamine receptor. Antipsychotics that bind really tightly are more likely to cause Parkinsonism and ones that don't bind it quite as tightly are less likely. It can take a while for it to go away, up to six months after stopping the medication, in fact, but just because it doesn't go away as soon as someone stops the medication, doesn't mean that it's not going to go away. It might just take a while, but by six months, pretty much all the cases go away unless it turns out that person actually has Parkinson's disease and we just unmasked it by the antipsychotic medication. The blocking of those dopamine receptors. Here, the anticholinergic medications, that same name I brought up before, benztropine can be effective for short-term use, and it is approved for both Parkinson's disease by the FDA and for drug-induced Parkinsonism.

(00:21:42): But again, this should not be a long-term treatment strategy for people. I see a lot of people with Parkinson's disease that are referred to me by movement disorder neurologists, and when I say a lot, I mean dozens, hundreds of people over time, and once I asked one of my friends who's a movement disorder neurologist who sends me a lot of these patients, how come I never see any of the Parkinson's patients you send me on benztropine? I've not seen a single one that you've put on that even though it's FDA approved for it. Oh my gosh, I've never put my Parkinson's patients on benztropine, Cogentin, the brand name. It's a terrible medication, it's got so many side effects, dry mouth, blurry vision, constipation, worsens their ability to think, things of that nature. I wouldn't do that to my Parkinson's patients, but in psychiatry, if we don't have that same perspective unfortunately.

(00:22:31): Benztropine or Cogentin is extraordinarily widely prescribed among people living with psychiatric conditions, and if you're someone who has lived experience who's watching this, I see there's... Looking at about 400 people on the call. If there's any number of people living with psychiatric conditions in one place that are taking antipsychotics, there's probably a pretty decent percentage then that are on benztropine at any given time, unfortunately. Not to say that it should never be used, but again, like I mentioned with dystonia, there's a narrow spectrum of people for whom there should be the prophylaxis. Well, for Parkinsonism there is also a narrow spectrum, or just people on benztropine in general, there's a narrow spectrum of who in this day and age should be on benztropine for longer than a couple of weeks.

(00:23:21): And unfortunately we as healthcare providers haven't done a great job of sticking with that, that we are prescribing it much more widely than it should be. There is an alternative also FDA approved for drug-induced Parkinsonism called amantadine, and this says it has no side effects, but the side effect profile that it does have in my opinion at least, is a much more favorable one than for anticholinergic, so even if someone does longer-term treatment with a medication to treat Parkinsonism, it would not be benztropine in almost any circumstance. There are exceptions to everything in medicine, but I really try to stay away from benztropine or Cogentin as much as I possibly can. There are other anticholinergics, there's one called trihexfenidyl, Artane in the United States. That's very uncommonly used by far of all the anticholinergics. Probably 95% of those that prescribed are benztropine, which is why I say that one again and again.

Dr. Craig Chepke ([00:24:16](#)):

But now I wanted to get to tardive dyskinesia and really settle in here and talk about it because all the side effects that I talked about so far from antipsychotics are just that, side effects. A side effect means that it comes on when you start a medication, usually it has a dose relationship to higher the dose, the greater the side effect, but most importantly a side effect, it goes away if you take the medication away. And tardive dyskinesia unfortunately is persistent for most people. It's irreversible for most people. To break it down, what is tardive dyskinesia? Tardive is from the French word tardive. Think of it like I have kids and if my kids are late to school, they're marked tardy. Well, they're late and that's what tardive dyskinesia is. It comes on late, so it's an impairment of movement that comes on late and the type of movement is very widely variable.

([00:25:09](#)): I'll show you the localization diagram like I did the other ones in just a minute, but it can occur really in any part of the body. And so it occurs not just from antipsychotics, but anything that can cause the blocking of the dopamine receptor. Certain nausea medications like Metoclopramide, Reglan was the brand name for that. Also had a black box warning for potential to cause TD, and there are a couple other... Promethazine can cause it, prochlorperazine or compazine, but almost everything that is going to block the dopamine receptor is usually called an antipsychotic, and for our purposes, I'll probably just say antipsychotic. The movements themselves, the size of the movements, the frequency of them can be mild, moderate, or severe, but we'll talk about the... How big the movement is does not necessarily tell us how much an impact and severity of the condition tardive dyskinesia can cause. It has been demonstrated to have a social and psychological impact.

([00:26:13](#)): Once again, it's got the longest delay between starting medication and the symptoms. It can start as early as three months, which again, the latest one previously was Parkinsonism, which was up to three months and this starting at three months for adults. For people who are over the age of 60, it can be as soon as one month after starting the medication, but more commonly it can be years, and this can make it very difficult for both people with lived experience and their healthcare providers to put two and two together. If someone develops a movement, why would we think about a medication they may have started 10 years ago or 20 years ago? We think about things in medicine as cause and effect. I start a medication, a side effect occurs. Okay, well, side effect probably related to the medication onset, but with TD, given that it's most commonly years after, then we may not have that cause and effect relationship in mind, so it's incumbent upon us is the healthcare providers to remember that and think about it and just screen for it, which is what we'll talk about.

([00:27:14](#)): But once again, even with the movements, they may get better over time and get worse over time, they can fluctuate over time. Sometimes they say just like you can have a good hair day and a bad hair day, you can have a good TD day and a bad TD day. And in general though, they are persistent, irreversible for most people. A few percentage of people, if you take them off the antipsychotic, that may resolve, but for the vast majority, upwards over 90% of people, it will not. It may reduce the symptoms over time, but for that reason these days the guidelines generally recommend not to remove the antipsychotic because most of the time that's something that is highly beneficial to the person. We'll talk about what to do about it in a little bit.

([00:27:55](#)): What can it look like? Well, the lower third of the face is the most common area, so the smacking, pursing, it can be tongue thrusting. By the side movements of the tongue, can be the upper part of the face. Eyebrows, people blinking. There's a million different ways TD can present, but the lower third of the face and the face overall is the most common. The neck, shoulders, chest and hips it can be common as well, but not nearly as common. You can have shoulder shrugging, can be movement to the trunk, kind of twisting, dancing.

Dr. Craig Chepke (00:28:38): Could be tick-like in the neck or shoulder. Arms, hands, fingers, these are very commonplace too. Unlike the lithium tremor that I showed you earlier, the movements are irregular. This one is often referred to as piano playing fingers, so it's not the same thing over and over. The Tick, tock, tick, tock, tick, tock. It's irregular and that's one of the main differentiating points. And that can happen in the toes as well, in the feet. There can be tapping of the feet, there can be movements of the knees in and out, up and down.

(00:29:14): It can affect not just the muscles we see, but the muscles we can't see in the neck, shoulders, chest and hips area. I mentioned throat and diaphragm, so swallowing difficulties. The soft palate in the throat controls what we swallow. Does it go down into the esophagus, down to our stomach or does it go down into our lungs? There's a dyskinesia movement that when we're eating or drinking happens and it could flick the food or drink down into your windpipe instead of down to your stomach, and that's what we'd call an aspiration. That can be medically serious, that can potentially cause mortality, so this is not just a cosmetic illness. It can cause significant physical health problems. And with the movements in the legs and the trunk, that can impair balance and what we call gait, the ability to walk and move well and can lead to an increased risk of falls. This is a very serious medical condition, and again, not a side effect because if you take the medication away, overwhelmingly it does not go away.

(00:30:10): Think of it in terms of cigarettes and lung cancer. When someone smokes a cigarette and they get lung cancer, then you don't... In medicine, we don't think of lung cancer as a side effect of cigarette smoking. Cigarette smoking predisposes someone and contributes to developing lung cancer, but if you take the cigarettes away, lung cancer doesn't go away. It needs its own specific treatment. Similarly, if someone develops TD on an antipsychotic, take the antipsychotic away, it almost always doesn't go away because it's its own syndrome now, it's its own disease or diagnosis and it needs its own specific treatment. Talk about that momentarily. Well, what do we think causes it? Well, for some certain individuals, we don't know all the genetic components, but certainly there's something genetic about it because not everyone gets tardive dyskinesia, go through the frequency that it happens for people in a moment, but if the dopamine receptors are blocked, specifically the D-II dopamine receptor, which is the one we usually are modifying with antipsychotics, in those susceptible individuals then they become hypersensitive to dopamine.

(00:31:19): I indicated that with the figure on the right, it's like their brain is flooded with dopamine. They've just got too much dopamine in the brain, in the motor pathways specifically because there's different pathways in the brain, just like there's different highways in a city. And just because one highway can be dysfunctional, it's clogged, traffic's backed up and other pathways can be flowing just fine, so if you get too much dopamine in the motor pathway for some individuals, that's what we think is the first cause of tardive dyskinesia. In terms of how common it is, there's lots of different antipsychotics. We divide them up. I've mentioned them before briefly, first and second generation antipsychotics, but I have them listed out here for you so you can see some names, and again, these are all the generic names.

(00:32:03): Now, pretty much everything since 1990, that came out since 1990 is the second generation or atypical antipsychotics, and prior to that was the first generation or typical antipsychotics. If you're currently taking a first generation antipsychotic, it's about a 1 out of 3 risk. If the person is currently on a second generation but was on a first generation in the past, 20%, 1 out of 5, and then if they're on both together, which actually is not that uncommon among many people living with serious mental illness, then it's about almost a 1 in 5, 22.5%. If they've never been on a first generation, only on a second generation, then it's 7% roughly, which is 1 out of 14. 1 out of 14 is still not an insignificant number.

Dr. Ken Duckworth ([00:32:46](#)):

Quick question, Dr. Chepke.

Dr. Craig Chepke ([00:32:48](#)):

Yes.

Dr. Ken Duckworth ([00:32:48](#)):

Could you give people the broad strokes of the first generation versus the second generation? Just want to make sure people have a good handle on the category of what their family member or they may be taking. Thank you. Sorry to interrupt you.

Dr. Craig Chepke ([00:33:04](#)):

No problem. I was thinking, "Oh my gosh, am I out of time already and I've talked too long?" Much more glad it was that question. Yeah, the first generation ones, some of the most common ones would be haloperidol or Haldol was the brand name of it. Chlorpromazine, thiorazine was the first antipsychotic and still is maybe commonly used. Let me see. Some of the others that are common, fluphenazine. I would say most commonly, the most common first generation antipsychotics that are used today would be Haloperidol by far, loxapine, thiothixene, navane maybe. The first generation ones are, there's fewer of them used now, so the ones that I picked out are really the ones that are the ones we more commonly see. We can still see anything, but it's usually clustered to just a couple of the first generations that tend to be in use. The second generation ones, risperidone, Risperdal, probably the most common antipsychotic prescribed in the United States.

([00:34:11](#)): Olanzapine or Zyprexa, incredibly common still. Quetiapine, seroquel, extremely common. Aripiprazole, Abilify for many years was the most common second generation antipsychotic because it was not just... A misconception is that antipsychotics are only for people who have schizophrenia or other psychotic-related conditions, but especially the second generation antipsychotics, Aripiprazole is a great example, it's approved for schizophrenia but also for bipolar disorder, it's approved for major depressive disorder, Tourette syndrome, agitation and autism. It's got a wide variety of different indications and many of these second generation antipsychotics have that as well for major depressive disorder as [inaudible 00:34:55] antipsychotics. There's also Brexpiprazole or Rexalti, Cariprazine or Vraylar is the brand name of that. Brexpiprazole, which is Rexalti is also approved for agitation associated with dementia due to Alzheimer's disease, so there's a very wide spectrum of different indications that these medications are used for.

([00:35:15](#)): And so it's not just for people who have psychosis or schizophrenia. It can be for mood disorders. And in just a moment, I'll go to the risk factors for TD and having mood disorder is actually a risk factor, so all the ones that are to the right on this slide, the second generation antipsychotics, these are far and away the most predominant ones that are used today.

Dr. Ken Duckworth ([00:35:36](#)):

Thank you. Super helpful for that clarification. The talk is [inaudible 00:35:39].

Dr. Craig Chepke ([00:35:39](#)):

Yeah, thank you.

Dr. Ken Duckworth ([00:35:40](#)):

You're doing great on time and you're doing a great job. Thank you.

Dr. Craig Chepke ([00:35:44](#)):

Thanks again. Appreciate it. These are the ones that are going to be by far the most likely ones that are in use today, but even the risk has gone down pretty substantially from the first generation being a roughly 30% risk to 7% risk. Well, that's about a fourfold decrease, four times less likely. Well, that's good, but like I said, 1 out of 14, which is what the 7% represents, is still not a trivial insignificant amount. That's relatively common. Some psychiatrists or other psych providers might see 14 people per day that have an antipsychotics, so we should be diagnosing tardive dyskinesia pretty common if we're using any reasonable number of anti-psychotics. And also the other factor is that the number of prescriptions of antipsychotics over time not stayed steady. As there have been more indications, most of the first generation anti-psychotics are only approved for schizophrenia, but as I mentioned, the second generations are approved for lots of different conditions.

([00:36:44](#)): There's been an over four times greater increase in the number of prescriptions, so the risk has gone down from 30 to 7%, by four times, but the number of prescriptions has gone up by four times, five times, maybe six times by this point, depending on how recent the data is, so tardive dyskinesia is not going away is the point. With the advent of the newer medications with lower risk, not low risk, and there is no anti-psychotic that has zero risk for tardive dyskinesia that's approved for any psychiatric condition other than there is one for Parkinson's disease psychosis called pimavanserin, which does not have any dopamine binding, so it's only approved for people with Parkinson's disease psychosis. As of today, anything other than that one that's approved as an anti-psychotic does have a risk of TD, even if it might be lower or might be higher, so we always have to think about it with the anti-psychotics.

([00:37:38](#)): At risk, the most important one is age, similar to Parkinsonism. At least a three times greater risk if a person's over 60 years old and it's not a linear increase over time. It tends to be fairly low, and then after 55, 60, that's when it starts to accelerate exponentially. Older people on anti-psychotics, we need to be very cautious about them and not to not use them because they can be life-saving treatments in many cases. We just have to be vigilant and monitor for it. There's a lot of other risk factors. If they did have one of the other movement disorder side effects early on, how long they're on medication, the higher doses. And the fourth one from the left, people with mood disorders are at greater risk than people with schizophrenia, so again, now that we're prescribing them as a field to more people with movement disorders, we really need to watch out.

([00:38:28](#)): The third one, women have a greater risk than men, especially post-menopausal women. Estrogen we believe seems to have some kind of protective role against tardive dyskinesia possibly. Some people who have developmental delay or if they've had a brain injury, brain injury could be a traumatic brain injury like having concussions, or it could be things like having had a stroke or things of that nature or MS, any sort of damage to the brain can potentially increase the risk. And then alcohol or substance use disorders as well. These are things that clinicians need to keep in mind when evaluating people's risk for tardive dyskinesia. What do we do? First screen for it. We as healthcare providers should be screening on a regular basis. There's multiple ways to screen for it. The gold standard formal examination is called the AIMS, the Abnormal Involuntary Movement Scale. There's recommendations that we should be doing that on a regular basis.

Dr. Craig Chepke (00:39:22):

Some studies though indicate that only 11% of patients taking an antipsychotic have regular TD screenings, so before starting the antipsychotic, the AIMS exam should be done. The AIMS takes several minutes, three, four or five minutes, so it's something that we have a person open their mouth, stick out their tongue, walk, do certain activation maneuvers we call them. There's a whole routine and ritual associated with it. And then how often it should be done depends on the various factors. Can be from every 6 to 12 months for the average person, for the people at higher risk could be every 3 to 6 months, but then we should be as healthcare providers looking for it in between. Those downward pointing yellow arrows are indicate if someone is seen by a psychiatric provider on a monthly basis, how many semi-structured exams, so not the full AIMS that takes five minutes or something like that, but just a quick little screening test?

(00:40:19): For me I have people who I see hold their hands up and then tap their thumb against their other four fingers back and forth, and if I see that that causes them to start having some of the movements of TD, then I go and do a full AIMS. If I don't see anything, doesn't mean they don't have it, but at least I've screened for it, I've looked for it, and so we should be doing that, these guidelines recommend with every person on the antipsychotic, every visit that we see them for. If you're seeing monthly, then for every 12 months, if we're doing AIMS every 12 months, we should be doing a semi-structured exam 11 times per year. And then if we do find movements consistent with TD, because there's no diagnostic test, the AIMS exam doesn't tell us yes or no it's tardive dyskinesia, it's a clinical diagnosis, if we see movements that have the right characteristics in the context of being on a dopamine-blocking medication, the most important thing is, well, it's important to see, okay, well are the movements small?

(00:41:23): Are they big? Are they slow? Are they fast? But that doesn't define the severity. The severity is defined of the impact on the person's life because TD has been shown to have potential problems across every domain of a person's life. It can cause them to have job difficulties, difficulty with social interactions, physical problems. I mentioned the swallowing problems, potential choking on food as well, not being able to do fine motor control, like button buttons, putting in earrings, putting on makeup can be impacted by TD. Psychological distress can be increased as well, and then it can even exacerbate the underlying psychiatric condition. With someone with depression and then who develops TD, the abnormal movements can cause them to have the exacerbated depression.

(00:42:10): This is a case study that I wanted to share with you. This for the 67-year-old woman who presented for depression. She had bipolar disorder and had been hospitalized many times. She had not been on antipsychotic in three years at the time that I met her, but she had been on one for probably a couple of decades worth earlier in her life, and she was on a mood stabilizer and antidepressants, sleeping medications. Lives with her daughter, husband and her grandkids, she used to be active in the church choir, but what I found out was that she had movements in her hands and her mouth, and so the choir director said, "Hey, you're an alto. I see you singing during the soprano part. You're going to ruin our song. If you can't learn your part, get out." She had sang in the choir since she was a little girl and she was mortified, and so it was happening because she had the mouth movements that were involuntary, so the choir director thought that she was singing at the wrong part, but she wasn't.

(00:43:11): She stopped singing in the choir after decades of it and still went to the church services, and at the church services [inaudible 00:43:19] she was holding the church bulletin in her hand and because the movements in her hand's involuntary [inaudible 00:43:26] wrinkle and make noise, and so the people around her would shh, I'm here to hear the preacher's word, I'm not here to hear your paper. What are you nervous? Sit down. You're ruining the sermon. And she was so mortified she stopped going to church altogether.

Dr. Craig Chepke (00:43:41):

And she, as I mentioned, lives was with her daughter, daughter's husband and their children at the time. They were real young, preschool, kindergarten age. And I said, "When Halloween comes around, grandma doesn't even need a mask. She can be a monster." Because facial grimacing involuntarily. And even though the kids didn't mean anything by it, they were just... They're kids, they didn't know what they were saying, but it broke her heart. She went upstairs to the room that she was staying in, barely came out.

(00:44:10): That's why she lost 40 pounds over a six-month period, and if I hadn't have been in tune with thinking about tardive dyskinesia on my radar, I would've missed it altogether and might've just changed her mood, stabilized her, antidepressants, something like that, and she never would've gotten better. But I did diagnose TD in her and put her on an FDA approved treatment for TD, which we'll talk momentarily. And for her, what it meant, I haven't mentioned anything about an AIMS exam score, what it meant was that she got out of her room, started playing with her grandkids again, went back to church and is back singing in her choir.

(00:44:45): And there's data to back this up as well, not just my anecdotes. It's been shown in this study that people with TD reported significantly worse social, mental and physical functioning as well as lower quality of life. Again, you can take a look at these later if you're interested. Another case about how it can affect work performance, I practice in the Charlotte, North Carolina area, which is one of the biggest banking cities in the United States, and this one worked in banking. And banking is a very male dominated field, and so she had major depressive disorder and chronic migraine. She was referred to me by her neurologist for depression, anxiety, things that we would normally see psychiatric providers. Never had been on an antipsychotic before, but she had a use of promethazine, which is the anti-nausea medication for migraines. She had really horrible migraines. She took the promethazine daily or multiple times a day for years.

(00:45:32): I didn't notice any abnormal movements and I wasn't looking for them. She had never been on an antipsychotic, so I thought, "Well, what are the odds that she's going to have any TD or anything like that?" And she called back a week later and said that she had seen a commercial on TV that... Well, actually, so my mother is my secretary at my practice, my wife who's a social worker and I co-own the practice. My mom's my secretary, so it's a true family business, and I got the message from my mom Mrs. So-and-so called and said that her anxiety is getting worse and her TD is getting worse. Mom, you got that message wrong. She doesn't have TD, she's never even been on an antipsychotic. No, I know that you really know a lot about TD, so when I hear it, I know, I remember it. It's like, "All right, well, let me call her and talk to her."

(00:46:18): And the woman told me that she'd seen an ad on TV about tardive dyskinesia and said, "Oh my gosh, I have that." I called her back in and I did do the full AIMS exam, and when I really looked at it and did the exam the right way, I saw the movements. They were very infrequent, but they were kind of subtle, eyebrows were lifting a little bit, bit of lip puckering very infrequently every three or four seconds, something like that. And if I just looked at her briefly, I wouldn't notice it, but unless we think that this was a mild case of tardive dyskinesia, she was devastated by it because of working that male corporate job she was so worried that that was going flag her as having something wrong with her and she would never get promoted. She would set up her cell phone to video her all throughout the day that she would, in lunch or after work, she would scrub through the video that she had recorded.

Dr. Craig Chepke (00:47:18):

I think I had a good day today. I don't think I had any movements and oh, oh my God, no, I did see one. I was having movements, I didn't even notice it. And she would work herself up into a panic attack and then she would get depressed because she was afraid that she was never going to achieve her career goals that she wanted to. And she felt like if she lost her job, she would never be able to get another one, that she was unemployable because of the TD. That's why I say that the AIMS ain't nothing but a number. We can't go based off the number score of the AIMS, it's the impact. And fortunately, she did well with an VMAT-2 inhibitor as well, and again, there's data to back this up. There's a study that was done, they had actors that read the same script and they did it their normal way once, a second time where they were coached by movement disorder neurologists on how to do mild to moderate tardive dyskinesia movements.

(00:48:10):

It was given out as a survey and there was a statistically significantly greater risk of the people who watched the videos to say that the person would not be suitable for client-facing jobs for the ones who mimic TD versus the one... Even though it's the same exact person, the same script, just the mild to moderate TD movements made the individuals who received a survey feel that they were less likely to be suitable for client-facing jobs, less likely to be dating propositions, less likely to want to be friends with them. Lots of different stigma that was associated with it. Now, APA guidelines, American Psychiatric Association recommends that we only treat TD with an FDA-approved VMAT-2 inhibitor. That's a vesicular monoamine transporter type II. That's a little geeky, you don't need to know that out there if you're in the general population, but that's what it's called.

(00:49:03):

Overall is that the severity of the number of the rating scale doesn't matter, what matters is that it has an impact on the person. Like those stories that I told you, throw out the score on the rating scale. If there's an impact on the person it should be managed with, and these are the two FDA-approved treatments, deutetrabenazine and valbenazine are what they're called. The brand names of those are Austedo and Ingrezza. These are FDA-approved for adults with tardive dyskinesia, and this is what we should be treating the tardive dyskinesia with. How do we think they work? Well, VMAT-2 is that red pump there. It pumps the dopamine into the circle, which we call the vesicle, and in order for the dopamine to be released, it has to be pumped into that vesicle first. You put a VMAT-2 inhibitor in, it locks the ability for the dopamine to get pumped in, and so therefore less dopamine is released.

(00:49:56):

As I mentioned, this is a state where people's brains are flooded with dopamine and there's too much dopamine being released, and so if we reduce the release of dopamine, we believe we can improve the tardive dyskinesia. That's our best theory to how these medications work. Now, broadly, how do they work? Both work very well. I use both of them in my clinical practice and they both have very good efficacy. On the AIMS scale, the average for both medications for the people starting this study was about a 10, and both of them reduced the AIMS score by about 3 points by the end of the year for their respective studies, so about a 30% improvement. But remember, AIMS ain't nothing but a number. It's not how much the AIMS decreases, it's how much the improvement in quality of life and functionality happens and what it can enable someone to not just do, but get back to what they were doing before, because TD I found in people who I treat, it can profoundly decrease their quality of life.

Dr. Craig Chepke ([00:50:55](#)):

Fortunately, both of them have been shown to be safe and efficacious, both in clinical trials. As you see here, the side effects for each of them, there's a very favorable side effect profile. Not zero, all medications can have side effects, but in terms of stopping medication due to side effects, between 3 to 4% of people taking these medications stop the medication due to side effects. And usually we consider if something's 5% of people in a clinical trial stop taking it because of side effects, that's a really well-tolerated medication. And these are both well under that 5%. Anticholinergics do rear their ugly head though unfortunately like benztropine. They're FDA approved for treatment of Parkinsonism, but they do get prescribed for tardive dyskinesia, even though in the actual prescribing information the healthcare providers get, it tells them three times it's not recommended for use in people with tardive dyskinesia. It's useful for something called extrapyramidal disorders, which is a overly vague, unhelpful conglomeration of conditions, but it says accept tardive dyskinesia.

([00:51:59](#)):

And not only does it not help, it even says in the prescribing information it can worsen tardive dyskinesia and make the symptoms worse, so we really need to get this diagnosis right as healthcare providers to make sure that we're using the right tool and unlike the picture that I put up there, not use the wrong tool for the job. And the APA guidelines also highlight that. Why not? Why do Anticholinergics not work? Well, there's a balance between dopamine and acetylcholine, and if it's anticholinergics, then it increases the dopamine, so if you add an anticholinergic you reduce the acetylcholine, increase the dopamine, and then you see the brain's already flooded and now it's really super flooded. It's a tsunami of dopamine signaling in the brain, and that's why we think it makes the TD worse. That EPS, as I mentioned, extrapyramidal symptoms, this is one problem in the educational system for psychiatric providers that we've been taught that EPS is a thing and it's many different things.

([00:53:00](#)):

All the different movement disorders I talked about today, they could all be called EPS and that's not helpful, so to demystify it, this is a chart that I made where it lists some of the characteristics, how long it takes to start, what the features of movement are, and then what the potential treatments are. Now, it's not just the psychiatrist or other psychiatric provider that is or should be responsible for considering TD. Everyone in the healthcare provider circle, it takes a village of people to find, diagnose and treat TD, but psychiatric clinicians can handle 95% of it. There are some examples when a referral to a movement disorder neurologist may be beneficial, but by and large, the psychiatric clinicians were the ones who prescribed the medications, in most cases, that can cause TD, although other disciplines can as well. We should and can be responsible for diagnosing and treating almost all of it. That brings me to the end, and Ken has a lot of Q&A to ask me. Hopefully I've left us enough time to be able to have a good robust Q&A.

Dr. Ken Duckworth ([00:54:07](#)):

Fabulous talk. So much dense information. Again, the slides will be either emailed to you if you registered or on our website if you want to go back and look. A couple of questions had nothing to do really with today's talk, so I want to point out that we have a library of America's best researchers and thinkers. A question on Clozapine, we had Dr. Rob Cotes of Emory.

Dr. Craig Chepke ([00:54:30](#)):

[inaudible 00:54:32].

Dr. Ken Duckworth ([00:54:31](#)):

A question on lack of awareness of illness, Dr. Javier Amador, who's done more work in that space than anyone on planet earth. And so I just want you to know the good Dr. Chepke, we're going to stick with movement disorders today, but that doesn't mean that other people haven't answered your question, so I just wanted to call your attention to that. Dr. Chepke, a couple big takeaways. Very few people are getting AIMS exams. I worked in community mental health and we did our absolute best to give people AIMS exams who were taking antipsychotics. Now, who is qualified to do one? Can people ask for one? Is it the standard of care to get one? Thank you.

Dr. Craig Chepke ([00:55:12](#)):

Yes, I'll take the last part first. Is it standard of care to get one? Absolutely. Any guideline that you can find is going to recommend a... It usually will say a standardized screening test because the AIMS is not the only one. There's another one called the DISCUS, but the AIMS by far and away is the most common one. But yes, every guideline you can find recommends that the AIMS be done on a routine basis every 6 to 12 months generally, and yes, ask for one. If you're someone who is taking an antipsychotic and you're not getting AIMS exam done, I would ask my clinician to do one because that is standard of care. In terms of who's qualified? Anyone.

Dr. Ken Duckworth ([00:55:52](#)):

And who would you say... Psychiatrists, nurses, physician's assistants, who else has the capacity to do an AIMS exam?

Dr. Craig Chepke ([00:56:00](#)):

Really it can be anyone. I have heard over the past years that there are some states that put some limitations on these are the people who should be doing them, but there's really no reason that any member of the healthcare provider team can't be trained to do it. It's something that one does need to have some training to do, it's not extensive training, just half an hour even of just here's what the AIMS is, here's how to do it, here's how to score it. Maybe an hour to give a little bit extra practice, but it's really just with some basic instruction practice. Anyone on the treatment team can be trained to perform AIMS exams and commonly it is someone like a, not just a nurse, an RN nurse, but an LPN, a medical assistant can do AIMS and certainly physician assistants, nurse practitioners and physicians.

Dr. Ken Duckworth ([00:56:50](#)):

They emphasize it doesn't hurt. Somebody that's asked you to do some movements and observe you, there's no needles involved, there's no pain, because that 11% number is really appalling when you look-

Dr. Craig Chepke ([00:57:02](#)):

Agreed.

Dr. Ken Duckworth ([00:57:02](#)):

... at the impact of movement disorders upon people. And AIMS is a screening test for that. All right, next question. A lot of talk about Cogentin and a couple of questions said, "My son's on been on Cogentin, benztropine for years with no evidence of movements," so let's talk about that. How would you approach that problem with your prescribing psychiatrist?

Dr. Ken Duckworth ([00:57:25](#)):

Would you say, "Dr. Craig Chepke told me? I learned on a NAMI webinar. Why am I on it?" I understand that this happens, I saw it in community mental health myself, so how do you approach that if you're a person who's trying to reduce just the polypharmacy in your own life? Cogentin, of course, anticholinergic has cognitive side effects, can make it harder to remember things, so how would you approach that question? Seems like a very common problem.

Dr. Craig Chepke ([00:57:53](#)):

It is. It's all too common and the way I would recommend approaching it is just by going to the clinicians who's prescribing it and say, "Hey, I was looking at my medications and I just want to see, is... What is the reason I'm taking each one of my medications? I know I'm taking this medication for depression, this medication for whatever it is, but this one, this benztropine, I don't understand why I'm taking it. Can you explain to me why I'm taking it and is it necessary or not for me to continue taking this?" I think everyone should feel empowered to be able to ask those types of questions. You shouldn't be asked to take a medication that you have no understanding as to why you're taking it and is it necessary or not, and there should be a... I'd say there should be a darn good explanation for every single medication on someone's med list as to why. And if there's not one, then we should think about what we call de-prescribing, taking the medication off.

([00:58:46](#)):

Now that doesn't mean just stopping it and definitely please no one out there stop benztropine, Cogentin abruptly. It's not medically dangerous in terms of being life-threatening or anything like that, but it is very unpleasant. Just like certain antidepressants, if you stop them too quickly, you can feel like you've got the flu basically, something like that. You just feel miserable. That's how one often feels if they stop an anticholinergic abruptly, so something that requires a long slow taper off of, and that should be of course done in conjunction with your healthcare provider who is prescribing it, so definitely talk to your healthcare provider who's prescribing it. Ask the reasons why they're on it, and if it's not something that is necessary, then can we talk about ways that we can taper off of this?

Dr. Ken Duckworth ([00:59:29](#)):

Do the new antipsychotic medication treatments impact the positive effects of antipsychotics or do they simply attend to the tardive dyskinesia? I think this question relates to if they're doing stuff, is there also a downside to the treatment arm?

Dr. Craig Chepke ([00:59:51](#)):

See, if I understand the question right, it's that are newer antipsychotics less likely to cause movement disorders? Is that-

Dr. Ken Duckworth ([00:59:57](#)):

No, the treatments for tardive dyskinesia.

Dr. Craig Chepke ([00:59:59](#)):

Oh, the VMAT-2 inhibitors?

Dr. Ken Duckworth ([01:00:00](#)):

Those two treatments, they're FDA A approved, do they have an impact on the efficacy of the antipsychotic?

Dr. Craig Chepke ([01:00:08](#)):

Ah, okay. Gotcha. Great. Okay, now I understand the question, so two important-

Dr. Ken Duckworth ([01:00:14](#)):

Sorry I wasn't clear.

Dr. Craig Chepke ([01:00:14](#)):

No, no, I got it now. Two important points to point out here. One is that both of those two medications were studied with the antipsychotics being unchanged, so one requirement of the study was that there was no change to them. That is very important that we, as I mentioned, it's usually ineffective to stop the antipsychotic in most cases and can put the person's mental stability at risk. And so we don't have to do that with the VMAT-2 inhibitors, tetrabenazine and valbenazine. We can keep the antipsychotic on board that kept them well without having to change it, and the studies for those two drugs did show it did not impact the efficacy. There was no increase in depression, anxiety [inaudible 01:00:54] symptoms, the psychotic symptoms. No increase in suicidality.

([01:00:57](#)): Older VMAT-2 inhibitors that are not approved for tardive dyskinesia by the FDA did have an increase in suicidality and depression, but that was in the Huntington's disease population. And both tetrabenazine and valbenazine are also approved for Huntington's disease Korea, and in those conditions they have a black box warning for the potential increase of depression or suicidality. But those did not apply for tardive dyskinesia. There was no worsening of their psychiatric stability, so no lessening of the efficacy.

Dr. Ken Duckworth ([01:01:30](#)):

Got it. How do I convince my psychiatrist that my valproic acid or Depakote may be causing tremor? Same question with some of the antidepressants. Again, in this talk, we can't cover everything, but this seems like an important area to talk about.

Dr. Craig Chepke ([01:01:46](#)):

Well, valproic acid, I would hope you wouldn't have to do a whole lot convincing because that is very, very highly associated with tremor, and also I want to point out that the valproic acid, even though it's not an antipsychotic, does not bind to the dopamine receptors in the traditional way that we talked about, does have a pretty strong association with drug-induced Parkinsonism for some people. It's not the majority of people who take valproic acid or Depakote, but this is something that is known for those of us who do have a interest for specialty movement disorders that valproic acid can cause drug-induced parkinsonism, but tremor very, very common with or without Parkinsonism there.

Dr. Craig Chepke ([01:02:26](#)):

And then if it's an antidepressant or anti-psychotic that you think may be contributing to the tremor, it can be difficult, especially if the more medications someone has on board. But if there's a way to establish the timeframe that, okay, well, I didn't have the tremor before, but this started too long after I started the antidepressant, antipsychotic, whatever, or it got worse after the dose was increased... It all comes down to the relationship that the healthcare provider sets with the person and hopefully they should be engaging in a collaborative discussion. We have these terms like shared decision-making and motivational interviewing, and when I learned that those were things, that those had their own terms, I thought that's just how you practice medicine, that you have a give-and-take of information and we share the different options and person with lived experience and the-

Dr. Ken Duckworth ([01:03:28](#)):

It's good doctoring.

Dr. Craig Chepke ([01:03:28](#)):

... clinician come to a decision together. I didn't know we needed a buzzword for that, but that's unfortunately not how every practitioner practices, but it's how we all need to practice, that people with lived experience have vital information and they are the experts about what is going on with them. And we need to marry that with the expertise that the healthcare providers have about the medication's risks and benefits, and come together as a team to make all healthcare decisions.

Dr. Ken Duckworth ([01:03:57](#)):

Two questions about catatonia. How do you think about catatonia as a movement disorder and what might you suggest people think about?

Dr. Craig Chepke ([01:04:07](#)):

Catatonia for people who are unfamiliar is a condition. It can be associated with many different psychiatric disorders. Schizophrenia is a common one, but it can be associated with many different psychiatric conditions. It could be associated as a side effect of an antipsychotic maybe. Sometimes the antipsychotic can contribute to catatonia. Catatonia, what it is that the person is, and some people may be on surface level familiar with the term, but they are poorly interactive, they're kind of inwardly focused. They may be mute, they may have something called backseat flexibility that you can take them and reposition their arms anywhere and they'll continue to hold them out. They maintain the body posture just like a Gumby doll that you can bend and move in different ways and they keep it there. Very negativistic. The general treatment is with benzodiazepine medications and also many other things. If you're ever looking for a [inaudible 01:05:17] on catatonia, Dr. Stanley Caroff is a world renowned expert on catatonia, publishes frequently on it. Also an expert on TD and a lot of things. He's a brilliant guy. But very broad topic, I could go on for a while, but-

Dr. Ken Duckworth ([01:05:30](#)):

It's a big topic and we may revisit it. This gets to a different question. People have very specific questions. How might you approach getting a consultation from someone like you? We know we can't clone you. How might a person approach this? Would they go to a movement disorder center at an academic hospital? Is this a neurologic field? Many people were asking very specific questions in the Q&A, which I always respect. Want to make sure we send them to the right place, because we're not going to get to all of them. How do you think [inaudible 01:06:06].

Dr. Craig Chepke ([01:06:06](#)):

Well, first off, I want to say... Sure. First off, my wife would say, "Thank God they can't clone me because one of me is all that she can handle," but-

Dr. Ken Duckworth ([01:06:13](#)):

Yes, of course.

Dr. Craig Chepke ([01:06:18](#)):

As I mentioned, psychiatric providers really should be equipped and not all of them are. If your own psychiatric provider that you're seeing is not, then I would say the best bet would be to go to a movement disorder-trained neurologist, not just a general neurologist. Most general neurologists do not have the training or expertise in tardive dyskinesia. General neurologist is like a primary care provider. Primary care providers have to treat diabetes and cholesterol and CPD, asthma, everything, and so general neurologists have to treat migraine and MS and epilepsy, everything, and they probably don't have expertise in tardive dyskinesia. Whereas movement disorder specialty-trained neurologists have their general neurology training and then they do a special fellowship in movement disorders. They're often associated with academic medical centers and Parkinson's disease centers of excellence as they're called, but there are some that practice in private practice in the community.

([01:07:19](#)): But if it's going to be a neurologist, I would recommend asking for a movement disorder specialist. The thing is there are very few of them nationally and there are not enough. There's many people with Parkinson's disease and other movement disorders and comparatively fewer people with tardive dyskinesia, so it's hard to get appointments. It can be six, nine months to get an appointment with a movement disorder specialist, but then there are some psychiatrists and other psychiatric providers who do have extra levels of knowledge as well, so that is figuring out within your community if there's someone who is a psychiatric specialist but is well versed in movement disorders. And that's something that often gets around in a community of who has some special expertise in that, and that's happened in my own community is that other psychiatrists have sent patients over to me specifically to manage the TD because they know that I have expertise in this.

Dr. Ken Duckworth ([01:08:16](#)):

Frequently at a community mental health center, somebody takes this on as their subspecialty. And your psychiatrist, the medical director who's usually a psychiatrist of your community mental health center may know who that is, and the best response to a request for a consultation is, sure, let me see when I can get you in.

Dr. Craig Chepke ([01:08:37](#)):

Exactly.

Dr. Ken Duckworth ([01:08:37](#)):

How dare you ask another question. A lot of very specific questions, so you would say, "Go to a movement disorder specialist, ask your prescriber who would be a great resource to give them a second opinion."

Dr. Craig Chepke ([01:08:54](#)):

Well, first talk to them about it and make sure that... Because the psychiatric prescriber may have the ability to manage it, they may not have understood that it was a problem, like the case study that I told about the woman who I hadn't even considered it because she hadn't been on an antipsychotic, but she was on the nausea medication that could cause it. And then once I looked, boom, I found it right away, but I didn't look the first time because I didn't understand her risk factors. First step, talk to your own healthcare provider and see, hey, can you do something about this? And then if you can't do something about it, who can you get me to that can do something about this?

Dr. Ken Duckworth ([01:09:29](#)):

Right. A couple people ask for a percentage risk of been on antipsychotics for five years, first generation, and what you would say is your slide, which everybody will get the slide set, the slide will be posted in a week, you would say traditional first generation antipsychotics, about 30%. But if you had a mood disorder, it might go up. If you're older, that risk might go up. The more years you're on it might go up. Is that a safe statement?

Dr. Craig Chepke ([01:10:00](#)):

Yeah, And there's things that can make the risk go up and down, so there's the low potency. If it binds less tightly to the dopamine receptor, it just barely grabs on versus really very tightly. That can have a reduction of the risk, so there's a variety of factors that can make it go up or down, so that 30% is kind of a thumbnail. It was a meta-analysis of 40-some studies with over 11,000 patients, but there are also people who have been on first generation antipsychotics for 40 years and never get it, so that's the thing is we just don't understand the biology and the genetics of it well enough to be able to say, because some people you would think, my gosh, how have they never gotten TD? They've been on the highest dosages of three antipsychotics at a time for 40 years and they have no movement disorders. Some people within a few months of a medication can get it. Unfortunately, we need more research to be done.

Dr. Ken Duckworth ([01:11:00](#)):

Great. Well, I want to thank you for getting up at 3:30 in the morning in Japan, giving this talk across the biggest pond and for a comprehensive and thoughtful review. Let's go to the next slides before we close, and I just want to thank you for a great talk at an inconvenient time. In June, we're going to talk about warmlines, helplines, and crisis lines, including someone from the Trevor Project who will be talking about how to access crisis care and support. One person asked about update on psychedelic treatments and microdosing. Well, it turns out that person was anticipating our July Ask the Expert. This gentleman, Dimitri, will also be at the NAMI Convention in Denver, June 4, 5 and 6 if you want to meet him and talk with him. He's part of the MAPS program, which is really developing the best research on the potential benefits of psychedelics, but also to understand the risks, and of course, there is a phase three trial underway.

Dr. Ken Duckworth ([01:12:06](#)):

Let's do the next slide, please. Ah, this is NAMI's first book and all the royalties from the sales of our first book go Back to NAMI. What I did in the book is I interviewed real people who use their names and share what they have learned. That seems very ordinary and who would know that this was the first book to do that? It's very NAMI. If you've lived with something, you've likely learned something. We also have a lot of experts in the back of the book, many of whom appear on Ask the Expert. In question and answer form, do I really have to take these meds forever? How do you help somebody who doesn't see that they're sick? I was going for one comprehensive supportive guide. USA Today Best Seller, a fun project.

[\(01:12:56\)](#): Let's go to the next slide, please. But wait, there's more. There's a second book coming out in September and I'm delighted to report that I didn't write it. My associate medical director, Christine Crawford. This book is for parents and caregivers of younger kids and goes through all kinds of interviews with real parents, real teenagers, kids, teachers and experts in the child development field. That book will arrive on September the 10th. Let's go to the next slide, please. Our supporters for this have no input on the content of this, but there are people who support NAMI through giving a free Ask the Expert. I thought it was kind of fun that Delta Airlines was supporting movement disorders today. I thought that was kind of unusual. Let's go to the next slide, please. And I want to thank you for joining.

[\(01:13:52\)](#): Obviously this is not specific medical advice for you. These are educational webinars. If you're inclined to donate, we like that, but as you can see, we also have acquired some sponsors who underwrite the very popular Ask the Expert. Last slide. If you have thoughts or questions for me, my name is Ken. I work at NAMI. It's ken@nami.org. I have an agreement with human resources that we will not hire anyone else named Ken, and so I think that vanity license plate email will continue. I'm not Dr. Craig Chepke, but I am your chief medical officer and I consider it a great privilege. I get back to every person who emails, me. It might take me a bit, so be a little patient.

[\(01:14:38\)](#): Ask the Expert is our inbox run by the extremely capable Katie Harris and your thoughts for future ideas, experts you want to hear from, things that you feel should be developed in this. This is a community project and we're very grateful for your participation, 400 people today, and I'm sure we'll do well on future calls. With that, I want to say thank you Dr. Craig Chepke. I hope you get some rest in Japan and take good care, and thanks everybody for joining today.