Christine Crawford:

I'm so happy to see so many people logged on for this super important webinar, and I hope that you all are able to walk away with a wealth of knowledge because we are just so honored to have these amazing panelists here with us today. So hello everyone. Welcome to Today's Ask the Expert session. I'm Christine Crawford. And I am looking forward to hearing from our three panelists, one who's going to give us an amazing presentation, an overview about long-acting injectables, and then we're going to transition into a lively fireside chat in which we will have two individuals with lived experience, one from the caregivers perspective, and the other one from the individual who's actually gone through this, who has lived through this. And just so we can hear that perspective.

Again, I mentioned this is an important topic. Long-acting medications can play a life-changing role for many people living with serious mental health conditions, and yet they're often misunderstood. So I hope that this presentation today will provide some clarity, will help to provide you all with the facts, challenge some of the myths, and share practical insights that hopefully can help people and families to make informed and empowered decisions about treatment.

So first off, I'd like to introduce you all to Dr. John Kane. Now Dr. John Kane is one of the leading figures in psychiatry. He served as Chair of Psychiatry for 30 years at Zucker Hillside Hospital, and as the Inaugural Chair at the Zucker School of Medicine at Hofstra Northwell. He currently co-directs the Institute of Behavioral Research at the Feinstein Institute for Medical Research. He's a past president of several major psychiatric organizations. Dr. Kane has authored more than 900 peer reviewed papers and has led over 20 NIH funded studies, with a focus on schizophrenia, recovery and improving the quality and cost of care. His work has earned him many of the field's highest honors.

So with that, I will hand it over to Dr. Kane, and after that presentation, he'll be joined by Maye and Jason Jepsen. So Dr. Kane, take it away.

John M Kane:

Thank you so much. So I'm going to address facts, myths and misconceptions about long-acting antipsychotic medications. And just at the outset, I just want to remind everyone that there are many other areas in medicine where long-acting formulations are utilized such as diabetes and contraception and HIV, both prevention and treatment, migraine, multiple sclerosis. So we're fortunate actually to have the options of long-acting antipsychotic medications to treat an illness like schizophrenia. Let's go to the next slide, please.

So we're going to talk about the rationale for considering the use of long-acting medicines for maintenance treatment and the prevention of relapse. We want to discuss their benefits and risks and the different options that are available. And there are obstacles. So we're going to be talking about some of the reasons why clinicians and patients and families may hesitate at times to use long-acting medicines. But we want to make sure that everyone really has the appropriate information so they can participate in shared decision-making. Next slide please.

So these are my disclosures. I've been a consultant to many pharmaceutical companies. I've been involved in doing clinical trials with long-acting injectable medicines supported by both the pharmaceutical industry and also the National Institute of Mental Health. Next slide please.

So the first key question that we have to ask ourselves is why is continued medication necessary? None of us really want to take medicine on a long-term basis. So we have to understand, well, what's the rationale for this? And the rationale really is that once someone responds to an initial treatment episode with medication, and they're improved, they're better, let's say they're out of the hospital, they're back home. And the question then becomes, what can we do to prevent that from happening again? And this is where maintenance medication comes in.

So the slide in front of you represents a meta-analysis from many, many studies comparing antipsychotic drugs to placebo for relapse prevention. And the effect of these medications is very, very strong. This is one of the strongest effects that we see in medicine in general, not just in psychiatry. So the first thing we have to remind ourselves is that medication is very important for the prevention of relapse. Now that doesn't mean it's going to prevent a hundred percent of relapses. Some people may still relapse despite taking medication, but the difference between taking medicine and not taking medicine is enormous. Next slide please.

One of the concerns that we have about repeated relapse is that there are data suggesting that after a relapse, the response to medication is not as good as it was previously. And even when patients are treated with the same medicine that they had before, they may not respond as well once they've had a relapse. So we want to prevent that from happening. And obviously there are many other reasons why we want to prevent relapse. It's a crisis both for the patient and the family and the caregivers. It often leads to hospitalization. There's a problem in terms of whether it's school or work or friends, it can create a lot of difficulties that we'd really like to prevent. Next slide, please.

So one of the questions that we often get is if I'm taking my medicine. And I'm doing well, let's say I haven't had a relapse in a couple of years, can I stop taking the medicine? And the answer to that is generally that's not a good idea. Even though that's very tempting. And I think many people have difficulty with the idea of needing to continue to take medicine when they're feeling okay. But the important aspect here is that we're trying to prevent something from happening. The slide in front of you represents a 20-year follow-up that was done in about 9,000 patients in Scandinavia. And what these investigators did was try to determine whether there was any period over eight years where it was safe to stop medication. Let's go to the next slide.

And what they found was that for that eight year period, again, we're talking about following over 8,000 patients. There was really no period of time where it was considered safe to discontinue the medicine. So this is an important aspect when we talk about the need for continued medication. Next slide please.

Another study that was done in this case in Finland where 2500 individuals who had been hospitalized for the first time with a diagnosis of schizophrenia, were followed after they left the hospital looking at medical records, and one of the most striking findings was that within 60 days of leaving the hospital, about half the patients were no longer taking medicine. And I think non nonadherence, or the problems that people have in continuing to take medication is one of the biggest problems in healthcare in general. Not just in psychiatry, but whether we're talking about diabetes, or hypertension, or asthma, or epilepsy, or any other medical condition, we have a hard time taking medicine on a regular basis. I think it's just human nature.

One of the things we have to do is de-stigmatize nonadherence. Doesn't mean you're a bad person or a bad patient, if you have trouble taking medicine, it's human nature. So the other thing that they found in this study was that the use of long-acting injectable medicines was associated with a significantly lower risk of rehospitalization compared to the oral formulation of the exact same drug. So again, very powerful data suggesting the value of long-acting injectable antipsychotics. Next slide please.

So how do we assess adherence? When I'm talking to a patient and perhaps the family as well, how do I know whether or not the person is taking their medicine? Well, we usually ask, are you taking your medicine? But sometimes people, they don't remember if they've missed it or not. They may be embarrassed or they may not want to admit that they've really had difficulty taking the medicine. So we don't have any better measures. We can ask the family, but they don't necessarily know. We could go to the home and look in the medicine cabinet and see how much medicine is left. We can ask the pharmacy if someone came to get their prescription filled. We could draw blood and see if there's evidence of medication in the person's blood system. But those are all very, I think, difficult, particularly doing plasma drug levels. Or we could use a long-acting formulation where we know and the family knows and the patient knows in fact they did receive the medicine. And it's quite obvious when they don't. When someone fails to get their scheduled injection, we know and we can talk to the patient what happened, find out if there's something else that needs to be done. Next slide please.

And this obviously is a big issue for families as well because if you've lived through a hospitalization of a loved one, and then you're very concerned about preventing that from happening again. You're going to be asking them if they're taking their medicine or not. And when I'm being asked by my mother or father or brother or sister, am I taking my medicine? I'm probably going to get annoyed. And this can be a source of family tension. So when someone's receiving a long-acting formulation, we don't have to have those conversations or that kind of tension. So when clinicians don't know for sure if someone's taking their medicine or not, they may think that the person isn't responding, they may raise the dose, or change the medicine, or they may add other medicines, or they may consider, well, this patient isn't responding to medicine when in fact they actually haven't been taking it as prescribed. Next slide please.

An example of that is a study we did at my hospital. We had 97 patients who came to the emergency room in a state of relapse. And they were being admitted to the hospital. And we asked the clinicians, so was this patient taking his or her medicine or not? And at the same time, we drew blood levels to determine whether or not there was medicine in the person's system. And what we found is that clinicians got it wrong in both directions. Sometimes they thought the patient wasn't taking medicine when he or she actually was, and sometimes they thought the person was taking the medicine when they actually weren't. And it just points out how difficult it can be for us as clinicians to know for sure whether someone's taking their medicine. And that's a very important distinction. When someone is brought to an emergency room, we really want to know, did they relapse because they stopped taking their medicine, or did they relapse despite taking their medicine? That's a very important differential for us. Next slide, please.

This is an example I mentioned earlier that some patients might be considered as treatment resistant. That is they're not responding to the treatment as we would expect when in fact they haven't been taking the medicine. So this was a study that was done in London where 99 individuals, 99 patients were referred to a clinic as treatment resistant for the possible prescription of clozapine. The investigators did blood levels and found that 35% of the blood levels came back as subtherapeutic. So these patients might've been put on clozapine unnecessarily because the issue is they weren't really taking their medicine as prescribed. Next slide please.

And that's actually one of the reasons that the guidelines that was proposed by a consensus conference of experts around the world on treatment resistant schizophrenia was to make sure that we have evidence that someone is actually taking their medicine before we say that they're treatment resistant. And ideally, they should have a trial of a long-acting injectable medicine for at least four months before we say this person is treatment resistant.

The slide in front of you is from a meta-analysis that we published in Lancet Psychiatry a few years ago, looking at all of the data. So we're talking about well over 100,000 patients participating in various types of clinical trials. And the data are overwhelming in suggesting that long-acting injectable medicines can reduce the risk of relapse and the hospitalization in comparison to oral antipsychotic medicines. Next slide please.

So why are these medicines underutilized? And there are many reasons for this. One is that clinicians overestimate the degree of adherence. As I said, it can be very difficult to tell and we'd like to think that our patients are taking their medicine as we've recommended, but that's not necessarily the case. Some people think that giving injections is invasive or punitive like it's punishment. It's not punishment. The idea is we want to make sure that someone's getting the benefit of the medicine that is intended to help them. Some clinicians think well if I suggest a long-acting medicine to my patient, I'm basically saying to him that I don't trust him to take his medicine. That's not the issue here. The issue here is that we all have difficulty taking medicine on a regular basis, and the use of long-acting formulations just makes it much easier to get the desired benefit from the treatment.

I think often there's insufficient involvement of family members or peer counselors in these conversations, because when someone is first approached about receiving injections, their first reaction maybe, "No, I don't like, like needles. I really don't want to have to get an injection." And what we've seen is that yes, an injection may hurt a little bit, but we find that the pain diminishes over time. As someone gets used to it, they get more comfortable with it. So we get a flu shot. We don't refuse a flu shot because of the injection. And here there are a variety of long-acting formulations that are available now that can be given every other week, once a month, once every two months, once every three months, and once every six months. Various medications are available, so patients and families have a lot of options from which to choose.

And I think we need to make sure that all of our colleagues, all of our clinicians are educated about the use of these formulations. That's very important. And I think for patients and families, they should ask their clinicians, well, what about this? Is this appropriate for me? I'd like to learn more about this. And sometimes that doesn't happen because I've heard from a lot of families who say, "I didn't know that this was an option. And I think it sounds very interesting."

Next slide please. So one of the questions that we frequently get is, okay, you're giving this injection, it's going to last for not just days, but weeks or months, so are you giving a very high dose? And are there going to be side effects that we wouldn't see when we're taking pills every day? And the answer to that question is we're giving medicine that is released slowly over time. So there's not a very, very high amount of medicine going into someone's system. It's very slow release. And these various formulations are designed in such a way that sometimes they can last for two as I said before, for weeks or even months. We looked at the studies comparing medicines given orally and the same medicine given via a long-acting injection. And we did not see significant differences in the side effects. And this is the meta analysis involving almost 5,000 patients. So there's really no reason to fear that the long-acting medicines are going to be associated with more side effects than the same drug when it's given orally. Next slide please.

So there are many factors that influence the utilization of long-acting medicines. There's the evidence, and we talked about that earlier. I think the evidence is pretty compelling that there are advantages to the long-acting formulations. Clinicians need to know about the data. They need to be discussing it with patients and families. Patients and families need to feel that they have enough information on which to make decisions. And clinicians need to be able to give the injections. Who's giving it? Is there a nurse available? Is it going to be given some states, pharmacists can give injections. So there sometimes are logistic questions, but they should be easily surmounted. Next slide please.

So education is the key. As in many things. We want to make sure that everyone has a real understanding of the role of nonadherence and how common it is and what the consequences are. We want to be able to discuss the rationale for using long-acting formulations. Even early in the illness, I've heard some clinicians say, "Well, I want to see if the patient's adherent or not. And if they relapse a couple of times, then I'll know that I should use a long-acting medicine." Well, you don't want to wait for someone to have two or three relapses or hospitalizations before you decide to offer something that could prevent a relapse or a hospitalization. So we really need to understand the role that this can play and education is key. Next slide please.

So again, teamwork. All the clinical team, not just the prescriber, but also the people doing therapy or rehabilitation need to understand the rationale for utilizing a long-acting formulation. And everybody needs to really be trained in understanding that. And to understand the real world impact of nonadherence and how common it is. And also to be able to correct any misconceptions about long-acting injections. And if a patient or a family member has a negative attitude, let's try to understand, okay, what does that do to? And sometimes it's due to the fact that a person was taken to a hospital, and in the emergency room they were given an injection, maybe they were even held down and given an injection. And that's obviously a very traumatic experience. When we're talking about the long-acting injections, that's a very different phenomenon. It's not forcing someone to take medicine in the emergency room, it's having their agreement to receive medication via this route in a way that's much more sustainable. Next slide please.

So in conclusion, I just want to emphasize that relapse and rehospitalization remain all too common, even in the early phase of schizophrenia. And these outcomes have deleterious effects, interfering with recovery, poor response to subsequent treatment, personal and family trauma, healthcare costs, and nonadherence and medication taking is a major risk factor for relapse and hospitalization. We don't have great methods to detect nonadherence. We really rely on asking the patient, and that's not always reliable. Long-acting injectable medicines have been shown to enhance adherence and substantially reduce the risk of hospitalization. However, these treatments continue to be, in my opinion, underutilized in many, many settings. And I think the biggest obstacle is not patients and families, it's actually clinicians. They need to, in my opinion, they need to be aware of the advantages, they need to be able to participate in shared decision-making and provide the kind of information that patients and families need to have in order to make a really informed decision about something that's really important.

So thank you for your attention and let me turn it back to our host.

Christine Crawford:

Thank you so much, Dr. Kane for that informative presentation providing us that overview of long-acting injectables. I'm really looking forward to introducing our two other panelists today. So we have Jason Jepson, who is a writer and mental health advocate living in Myrtle Beach, South Carolina. He was diagnosed with schizoaffective disorder while serving in the US Army. Jason has dedicated himself to supporting others, particularly veterans. He's certified through NAMI's peer-to-peer program, and volunteers with the Shared Network and Students with Psychosis. Jason is a published author of both a memoir and poetry, and his personal accounts of living with schizophrenia have appeared in Schizophrenia Bulletin, The Washington Post, Newsweek and more. His advocacy is rooted in reducing stigma and encouraging others to seek the health they deserve. And he will be joined by his mom, Maye Jepson, who is a caregiver and a passionate advocate for mental health.

She and her husband being parents to Jason, and they're just so proud of him and everything that he has done. The two of them, her and her husband founded the Facebook group Parenting Through Mental Illness to provide resources and connection for families. She has a background in counseling and certification and patient leadership. And Maye now works as a care guide for Johnson & Johnson's Connected by Hope program, supporting families newly navigating schizophrenia. She also serves on the advisory board of Students with Psychosis, volunteers with the Share Network, and has presented with Jason at National NAMI Conferences. So thank you all for being here today. Thank you.

And you probably saw a little visitor who came in here, but it's after school time in Boston, and so I'm just navigating it. So I hope you guys can just roll with the punches here. So again, thank you so much for being here. Jason, and Maye, especially starting at Jason, I wonder if you could share briefly a little bit more about what brings you to this conversation about long acting antipsychotics. Tell us a little bit about your story and your personal experience, Jason, when it comes to LAIs.

Jason Jepson:

Well, I can't say enough good things about LAIs. I was concerned at the very beginning about getting a shot, but after the doctor suggested you don't have to take a pill if you have to take a shot every month, that sounded great to me. One less pill. And the shot is really not a big deal once you've had it several times. It's just one of the things you got to deal with recovery. But I was in the army. I joined the Army because stability healthcare and 911 was recent. This was back in 2003. And honestly, looking back, the stability part, maybe I was dealing with early mental illness. I wasn't a doctor then. I didn't know what was going on, but I joined the army for stability. And it really burst open after that in the army.

In basic training, I did a lot of push-ups. A lot of push-ups. It's called being smoked. And when you either stand out or you do something wrong, you have to do a bunch of push-ups until muscle failure where you just drop. And I did a lot of push-ups. And it was a struggle for me for basic and advance. But I was able to graduate, which very proud moment in my life, especially looking now considering all the chaos in my mind at the time. And I went to Fort Arran. I was 19D Cavalry Scout, which is in combat arms as in if you graduate basic advanced training and you go to your fourth studio and says, "You're going to Iraq, you're going to Afghanistan. That's just how it is."

And I don't know, I felt that I wasn't quite there. There was a little bit of a little break in my mind because of all the push-ups and the training and the trauma went along with that affected me. And I thought, I go to Fort Arran in six months, then get deployed to Iraq, and by then I'll be fixed. Everything will be fine. I will be the soldier that I should be. Well, I stood out at Fort Arran too. One way I stood out, I fell out of a run in the army, you are one formation, you're not individuals, you got to stay together, and I fell out of a run because of my foot pain, plantar fasciitis. And I was in severe pain. Pretty much crying. And they didn't like that. They don't like people to stand out in the army.

And I believe I was standing out and acting out and because of my schizophrenia, that really bursted after the hazing issue for being punished for acting out and standing out. And it was rough. With all the symptoms I was going on, I thought soldiers could see what was on my mind. I thought, I think it's called thought broadcasting. I thought they could see what was on my mind and I would blurt out what I think they were seeing. And I always thought they were conspiring against me. In fact, one of the first things I bought when I went to my forced duty station was a coffee pot. Had to have my coffee in the mornings. I just had to. And I thought my roommate actually put broken glass in the coffee pot. I never saw any, but I was for sure he's messing with my coffee pot.

And it was bad. I had chaos going on in my mind. And I decided to, well, I didn't decide, I thought God told me to go to the mental health on post. They sat me down to take a psychiatric test and it came back schizophrenia, so they took me to Balboa in San Diego and I pretty much was diagnosed with schizophrenia. And I went back home with my parents and I think they were doing some research on their own and finding everything they could about schizophrenia as good parents do. And they had no idea, when they opened that door for their baby boy, they had no idea what just came home to them.

Christine Crawford:

And I imagine that was quite overwhelming for your parents too. Maye, what was it like to see your son like that? And share your perspective of your observations of him during that time. And what was it like for you as a mom?

Maye Jepson:

Well, I can tell you that as a mom, and I've met so many moms who are exactly in the same position that I was in at that time. I was so scared because even though I had a counseling background myself, I did not expect mental illness to hit in our family. I know that one in four people are affected by mental illness, but somehow I was naive enough to think that it would be somebody else's family and not my family. So when Jason got his diagnosis, I began to research schizophrenia. And I looked online, I spent hours online looking up examples of people who had schizophrenia and learning as much as I could about it, because I wanted to be able to help my son.

I realized soon after he got home that we were not going to be able to love him out of this. We provided a wonderful home, I believe, for Jason, but this was something that was much bigger than we are, and it was going to take a lot more help to get him through this period of time. So in addition to learning as much as we could, my husband and I joined a parent group that our county mental health department offered. It was called Parents of Young People Who Are Not Cooperating With Their Medication. That was life, that was God send to us because now we were meeting people who were in the same situation that we were in.

And the one thing that I could not find online during that time when I was looking for any information about schizophrenia, I could not find any first person accounts. There were no interviews or videos of people who had schizophrenia, but who were talking about how they had moved into recovery. And we were only given one option when Jason was first diagnosed, and that was to take an oral medication. I had no idea that anything else even existed. I probably knew that people who had diabetes took shots, injectables for their disability, but I didn't know that there was anything like a long-acting injectable for mental illness. So we were over 10 years into Jason's diagnosis before the idea of a long-acting injectable was ever presented to us.

Christine Crawford:

That's amazing. 10 years.

Maye Jepson:

Isn't that-

Christine Crawford:

10 years.

Maye Jepson:

... it is amazing.

Christine Crawford:

Such a long time.

Maye Jepson:

And so he would try several different oral medications and they might work for a while. And of course there was always the issue of was he taking it? And Dr. Kane just really nailed it when he said, "You don't know for sure if they're taking it." Jason had some cognitive issues with his schizophrenia. So sometimes I would call him and say, "Did you take your medicine tonight?" And he would say, "I'm not sure. I forgot if I took it or not." And so we didn't know what to do except to take another pill. Take another one.

And so we did not know what to do. And so we had all the problems that Dr. Kane mentioned with the oral medication. And so finally about 10 years in, Jason was hospitalized because of suicidal ideations. And his psychiatrist at that time mentioned him taking a long-acting injectable. That was my first introduction. And our first introduction to long-acting injectables.

Christine Crawford:

And Jason, I'm curious, when you were first introduced to long-acting injectables, what sort of thoughts did you have or concerns that you had? And were any of those based on the myths that you later found out weren't true?

Jason Jepson:

I think one comes to mind, it's when I take the pill, I know this happens. The shot, it's long acting injectable. It takes time, it's time release. So I question that. But again, well, my mom and I tried different medication, my medication. And it seemed so easy. I'm sure if there are patients out there, I'm sure they have, I do take other pills, but I'm sure they have that pill organizer. And it was so unstressful to have one less pill to take at night. And I like that. And I especially like it now. It's once a month. I see my nurse practitioner once a month, and I couldn't ask for better care from the VA. But the concern is that I didn't see it going inside me all the time, I guess is what I'm trying to say.

Christine Crawford:

Yeah, that makes a lot of sense too, because I imagine for a lot of people they're so used to taking a pill and knowing that they're taking something, but a shot is a completely different experience like you had mentioned. And Maye, as his mom, what fears did you have or any misconceptions that your family initially had about him receiving the shot?

Maye Jepson:

Well, when the doctor first introduced the idea of an LAI, I actually was very hopeful because it was stressful for us as Jason's parents to call. We called every single night to ask if he had taken his pill, because many times he had not remembered to take it. So we would call to remind him to take it. I'm sure that came across as nagging. Who wants their mom or dad calling them, or their husband or someone calling them to ask, have you taken your pill tonight? So we didn't have to do that anymore. I was very hopeful that this would work, that this was something very different, but that it would work for Jason. And it was very much a relief to know that. But I also, I was a little skeptical too, because I had never heard of this before. No doctor had ever mentioned it up to this point.

And so I was a little bit wondered if this could really be as good as it sounded like it would be. But anyway, listen, I cannot be a more enthusiastic supporter because of what I have seen in Jason's life as a result of his taking the LAI. I know that it improved our relationship with each other because I did not have to again, be the nagging mom. We could treat each other and have more of an adult kind of a relationship rather than a mom and a child because he's not a child. He deserves to be responsible for himself and for his own medications. And so in that way, it also was a great help to us as his parents.

Christine Crawford:

Yeah and as his parents-

Jason Jepson:

I would like-

Christine Crawford:

Oh, go ahead, Jason.

Jason Jepson:

I would like to say the structure and the stability I was searching for in the army I got with an LAI. My own daily routine I've made for myself, I stick to it, and it helps me manage these symptoms. It's just been a wonderful medication for me.

Christine Crawford:

Yes. And it was helpful to hear about how your mom, your parents were trying to support you during this time, and to hear about the concern about being a nagging mom and that having an impact on the dynamics between you all. Dr. Kane, I want to pull you into this from a clinical perspective, how can parents engage with their adult children around possibly starting an LAI, or to provide them with meaningful support if they have this knowledge about LAIs?

John M Kane:

Yeah, I think that's very important. So as I said, education is really key for everybody, including the clinical team, patients, families, everybody. And I think it's very important that you initiate these conversations with your clinicians too. If somebody hasn't mentioned this to you, then you should ask them about it. I think sometimes patients and families are a little bit intimidated to ask the doctor about something, but you shouldn't be. It's really they're there to help you. And it's a perfectly reasonable question to ask. What about LAIs? I hear there are different options and let's talk about it.

Christine Crawford:

And it's so important for parents to feel empowered to engage in not only conversations with their adult children, but with the clinicians too, so that they can develop that deeper understanding. Because if they have developed a certain comfort level with a certain treatment option, then they'll be more comfortable and confident supporting their loved one as they're navigating this. And Jason, for some of the parents that we have on the call, do you happen to have any advice for our parents so that they can better understand what it's like for their child to navigate this? And what it's like to, would it be helpful to hear someone who is getting the support from their parents, what would be helpful for parents to say to their kids to support them as they're trying to navigate whether they should get an LAI, or to better understand their experience?

Jason Jepson:

LAI helps you give peace of mind from a quiet mind. Now quiet mind, you probably want a quiet silence. That is valuable to me when all I do is watch TV and there's no chaos or stuff that's not supposed to be that going on in my mind. And I really believe LAIs takes the stress out of medication too.

Christine Crawford:

Yeah, absolutely. And the other thing too is that we know that early intervention is really, really important. We always talk about it whenever we're having a conversation of those who are living with serious mental illness. And Dr. Kane, I wonder if you could just provide a brief overview of some of the warning signs that parents can look out for. And then Maye, would love to hear your thoughts afterwards about what were some of the signs that you had picked up on prior to everything that Jason had shared before. So Dr. Kane.

John M Kane:

Sure. So some of the warning signs can be things like sleep difficulty, change in interactions. Someone seems to be annoyed or angry, or very sensitive, or feeling suspicious, and that something just changed in their behavior. It may be subtle. But those are the early signs. And it's also important for families and patients to realize that each individual may have a characteristic sequence of events when they're beginning to experience the illness again. So some people, it starts with irritability, other people, it starts with anxiety, other people it starts with difficulty sleeping. So if you're aware of what's been the pattern in the past, sometimes that can help you identify something in the future. But a lot of this is also just observation and communication.

And as you said, I think it's really important to try to intervene early and prevent something from getting worse and worse.

Maye Jepson:

Yes, I completely agree with that Dr. Kane, because before Jason went into the Army, anyone who knew him would've described him as being a very kind, thoughtful person who always looked out for the other person. But the young man who came home to us was extremely angry. He was angry about everything. And of course anything that we tried to do to help that just fed that anger. And he became angrier and angrier, and it sounds simple to me. Just take this pill, this is going to make you feel better and you're not going to feel so angry. But to him, the anger was just a part of the whole spectrum of schizophrenia, of hearing voices, which I knew that he was hearing voices because I could see him when we were sitting in a room, he might be just sitting there moving his lips. He would be speaking silently to the voices.

And also knew that he had delusions because he was thinking he could be an informant for the police. So he would go and do stakeouts, hoping to get money from Crime Stoppers. He was paranoid about someone messing with his truck. All those things were not like this person before. So there were clear signs when he came home. And while he was this angry person, one important thing that I always try to tell parents is filter every single comment that you get from your loved one through the lens of mental illness. This is not the same person. This is not the same person that you have loved and that you saw grow up. This is a different person who's having symptoms that they cannot control. That's why it's so important to get them on the right at the very beginning.

And I wish that that had been given to us, an LAI as a treatment option right in the beginning because he wasn't going to take any other kind of oral pill. He would forget or he would not be as adherent as he needed to be. So that is very important to try to, this is not the same person who's speaking to you in these angry, hateful, sometimes words that they use. And so patience is a very important trait to be able to pull out. Also, taking care of yourself as a caregiver so that you can be in better shape to take care of your loved ones. I journaled every single day. I have these journals still. Sometimes just writing down the things that I saw in Jason that were so different because I used those when I went with him to a doctor's appointment to show the doctor what was going on. These things are happening in his life because sometimes he couldn't even really describe what was going on. And so I would have these journals that I kept.

And one other important thing I want to say is that in that family support group that we were going to, that our county mental health offered, a clinical psychologist who facilitated that group said this. He said, "It's going to take an army of helpers now and forever." And you know what? I took that to heart. We did not try to keep Jason's diagnosis a secret. In fact, we decided that we were going to fight the stigma that was out there. And so we did that. We let our friends and our loved ones know that Jason had been diagnosed with a brain disorder that he was going to have for the rest of his life. That he would have to take medication, but that he was going to get better because we were going to form a team that was going to support him all the way through.

And I believe that that is the biggest difference. What we were willing to give to him as parents in that there was nothing he was ever going to do that would stop us from trying to help him get the help that he needed.

Christine Crawford:

Everything that you touched upon is so important for everyone on this call to hear. And I think one of the things that stood out to me was your strong sense of urgency to inform people in your community about what was going on with Jason. Not only so that Jason could get the help and support that he needed, but you guys as parents to get the help and support that you needed to take care of yourselves, to fill up your cup, so that you could be able to help Jason navigate through all of this. And that is tremendous, and that's something that a lot of parents really struggle with being able to do. They communicate what it is that they're going through.

And so I'm so happy that you had mentioned that. And Dr. Kane, one of the things that often comes up for both parents as well as for patients is to understand when in the treatment course or when one has a diagnosis of a psychotic disorder, should they be introduced to the long acting later on in the course of their condition, early on? Any guidance that you can provide the people on this call about when we should start talking about LAIs?

John M Kane:

I think we should start talking about it very, very early on. And I think it's information that should be available to patients and families that, look, we have this illness, we're trying to treat it. We know that medication can be very helpful, but everyone has trouble taking medicine on a regular basis. It's human nature. We need to destigmatize nonadherence, as I said before. It doesn't mean you're a bad person or bad patient, it's human nature. I forget, Maye was talking about sometimes Jason would say, "I don't remember." That happens to me. It happens to all of us. So having a way to manage this I think is really important.

So I would say at the very beginning of the illness and the diagnosis, we should discuss, okay, we're going to start probably with oral medicine initially, but once you're better, once we figured out if the medicine's working, if we have the dose right, if we're managing the side effects, and then we go into the maintenance phase, that's when we introduce an LAI. Whether it's after one episode or after two episodes, we want to prevent subsequent episodes. We don't want to let somebody relapse if we can prevent that. And that's particularly in the early illness, I think it's very, very important.

Maye Jepson:

And I also think that when a person does relapse, that is another hit to their self-esteem. And that's another trauma that happens. "I'm no good, I can't even do this." And that hit that has come with not knowing what's for certain in your life and what's not. And anytime a person relapses again, they're hit with this, "I'm no good. I cannot conquer this." And it's so important for people to know that with an LAI or with oral medication, if that's working for you and you have no problems with it, that's fine. But many, many people do have a problem with taking an oral pill. And those are the people that I would love to say to you, just try this.

And if you're a mom or a dad or a caregiver out there, and I like to call them trust partners because as you can see, my son is not a baby, he's not a teenager. I'm not his caregiver now, but I am his trust partner. He trusts me. And that is so important if you're having an adult to an adult relationship. Jason trusts me to give him good advice.

Jason Jepson:

To be honest with me.

Maye Jepson:

That didn't just happen, but he trusts me. And helping someone to understand that this LAI, this injection is going to help you with those symptoms that you're experiencing. This will help to calm the voices. This will help you to not be afraid so much. And so talking about the symptoms and how the LAIs will help those symptoms is a good way sometimes to get someone to agree to try an LAI.

Christine Crawford:

And Jason, with the work that you do with veterans, how do you have those conversations with them given that there's so much stigma that's associated with mental health treatment with LAIs, and we're hearing about how helpful these medications are. How do you have these conversations with the veterans that you work with?

Jason Jepson:

With my experience, I did have a group therapy at the Richmond VA. And with veterans, we talk about the meds we've taken and it's, "Well, that looks like it's walking for you," kind of thing. I don't like advising people because I just know what works for me because every size doesn't fit all. And I was the chair for the veterans counselor at the Richmond VA too. And group therapy would help with understanding other effects of medication for the patient. Unfortunately we cannot have the great mind Dr. Kane has, but try group therapy and just get the conversation going about medication. Like mom said, trust happens with group therapy because you have the same symptoms, you may be dealing with the same thing.

Christine Crawford:

Absolutely. Absolutely.

John M Kane:

I think peer counseling is very important also. And that's what you were doing to a large extent.

Christine Crawford:

Absolutely. So we had this amazing conversation talking about LAIs, their utility, how helpful they are, some of the benefits associated with it, and how helpful it can be in one's mental health journey and the recovery. So Dr. Kane, one question that I have for you as we're going to transition into the Q&A session and then Maye and Jason, I have a question for you as well. But you've spent your entire career studying mental health conditions, treatment, recovery. I wonder what gives you the most hope about the future for young people who are affected by mental illness. And what gives you hope when it comes to the families who are supporting these individuals?

John M Kane:

I think we've come a long way in understanding these illnesses. They're not caused by someone's, years ago it was bad parenting. That's what caused these illnesses. We know that's completely untrue. These are no blame illnesses, if I can put it that way. If I develop diabetes, it's not necessarily my fault. But we have to understand that mental illnesses, these brain disorders are a real challenge for everybody. But I think we've come a long way and understanding that, being able to talk about it openly. We have some success in destigmatizing it. I think we still have a ways to go. But many people, like the people we're talking to today are willing to be open about it and have these conversations. I think that's critically important. That would not have been the case 30 years ago. So I think that's very helpful.

I think we are developing more medicines and better medicines. And now we've talked about the options that we have with long-acting formulations. I have colleagues in other branches of medicine that wish they had the option of offering that to their patients, but they don't. So in a way, we're lucky that we have these options and we really should take advantage of them. And I think there's a lot more that can be done. Even with those options, they're not being taken advantage of.

Christine Crawford:

Absolutely. Maye what gives you hope?

Maye Jepson:

Oh, I can tell you what gives me hope. Just looking at that young man right there, that gives me hope. Because I remember what he was like when he came home from the army. I remember those early days. And now I look at him and I see this kid who has grown into a man of purpose, who has a very productive life, who enjoys his life, who we, his parents love being around him and living near enough to him to go to the movies, and go out to dinner, and go on trips. We love being with him. That gives me hope. But I want the hope to extend from our family into every single family that's listening here today. That there is hope for your loved one. And that hope may very well be possible through taking an LAI. And if that is the case, talk to your doctor on the very next visit about the possibility of an LAI and how that might help your loved one.

Jason Jepson:

Well I, with the help of my parents, I was able to find purpose in my schizophrenia advocacy. I'm able to write what it's like day-to-day living with schizophrenia, which I think is very valuable. I don't get paid for it, but I think it's valuable for people to hear. And occasionally we have speaking engagements like this where I can share my lived experience with schizophrenia too. This time with LAIs. And I'm hopeful that if you try it, you will love the convenience.

Christine Crawford:

Beautiful, wonderful. Thank you so, so much Maye and Jason for spending time with us, for being open and honest about what this journey has looked like for you and for your family. And I'm 1000% certain that your story has made an impact on at least one person here, if not many others. So thank you and thank you Dr. Kane for your expertise and your wisdom, really appreciate having you here. So our audience wants to tap into this wealth of knowledge that's on the screen here, and we've received a number of questions, so keep the questions coming in. We've gotten a lot of questions.

But Dr. Kane, the first question I have is for you, and it's one that a lot of people are curious about. Now there are different long-acting injectables that people can receive in different frequencies. There's ones where you can get it every few weeks or every few months. So how should patients think about these injections that can be given over the course of a few months or how do people make those decisions? And also, if you're taking one that's going to last for eight weeks or so, you're going to get a higher dose of the medicine. So does that put you more at risk for developing side effects like tardive dyskinesia?

John M Kane:

Sure. Those are very important considerations. So what we usually recommend is first you have to decide what medicine is best for that person. And that's probably going to start with an oral formulation, so that you can decide if the person's responding well, are they having side effects, are you getting the dosage right? And then you're going to move to the long-acting formulation. And the decision as to what the interval is may change over time. So I may start out with once a month and see am I comfortable with that? And then if I am, maybe I want to go to once every other month or once every three months. But I think that's going to be a process. I don't think you go right away to the longer interval. And as Jason said, it's a matter of getting comfortable also. The first injection hurts a little bit, then the next one hurts less, and you get comfortable with it. And the convenience becomes more and more obvious.

And then your second part of the question was, are we giving a very high dose that's going to cause more side effects? And no, the answer is we're not. We're giving a slow release formulation. And we did a meta-analysis looking at several thousand patients comparing the side effects on the oral formulation to the side effects on the LAI of the exact same drug. And we did not see a difference. So I don't think the LAIs are associated with any more side effects, whether it be part of dyskinesia, or weight gain, or sedation, or anything like that. The difference though, in a way is that we have better control over the dose when we're giving a long acting because we know exactly that the patient's getting it. And as I said, sometimes the clinicians are confused because they think the person isn't responding when in fact they're not taking it regularly, so they end up raising the dose and that's not really the appropriate response so yeah.

Christine Crawford:

That's so important for people to hear because there are a lot of questions about side effects. But to know that this is a medicine that will slowly be released in a control manner, studies have already been done to show that you don't have more side effects if you receive an LAI. So I'm really happy that you're able to clear that up. And one other question for you on the same topic, there are some questions about people who are concerned that once they get on the LAI, they might have a reaction, a bad reaction to it, and then the medicine is in their system for a month. So how do people navigate that? Or is there anything that you can share to help mitigate some of the worries or concerns around that?

John M Kane:

Sure. Well, usually someone's going to have had some experience with the oral medicine first just to make sure that they're tolerating it well. They don't have any reaction. What we've seen though, so probably neuroleptic malignant syndrome, which the audience may not be familiar with, but this is a rare side effect of antipsychotic drugs, which can be quite serious. And the recommendation generally when that happens is to stop the medicine that the person is on. So if someone on a long-acting formulation, you can't stop it immediately. As you said, it's in their system, it may be there for a month or longer.

So we've done a lot of research on this issue looking at all of the cases worldwide that have been reported. And we did not find a difference between those patients who developed this condition on LAIs versus those patients who developed this condition on oral medicine. No difference in outcome. Even though the recommendation is to stop the medicine. So the other point that I would emphasize is that the likelihood of this occurring when someone's receiving a long-acting injectable medicine is very, very low, particularly with the second generation medication. Very, very low. So I would say that's the most extreme example when we'd say we want to stop the medicine, but we can't. Turns out that's not having the consequences that we might be afraid of.

You mentioned tardive dyskinesia earlier, there's some preliminary evidence out of Japan that the patient's getting the long-acting injectable medicines might actually be at lower risk for tardive dyskinesia than the patient's getting the oral medicine. And that might have to do with the irregularity of people taking the oral medicine. So they're going on and off and on and off. When they're on the long-acting injectable, they're really on a stable dose over time, and that may be one of the factors that could reduce the risk of tardive dyskinesia. Also, the second generation medicines have a lower risk of tardive dyskinesia than the older medicines, so that's good news as well.

Christine Crawford:

Perfect. And I just want to round out this conversation about medications, and Maye and Jason, I'll pull you in a few. But there have been some questions coming from the audience about drug interactions or if LAIs would interact with someone who might be using cannabis or using any street drugs. So can you talk about some concerns around drug interactions, whether that's prescribed medications or other things, substances like marijuana that people use regularly and even cigarettes, smoking cigarettes?

John M Kane:

Sure. So in terms of other medicines that are prescribed, that's one of the things the clinician has to evaluate. Are we using multiple medicines that might interact in some way? It's unlikely, but it's possible, but that's a clinical judgment. In terms of substances of abuse like marijuana or cocaine or amphetamine or what have you. In my view, I am more comfortable if I think my patient is at risk for using those substances. I'm more comfortable knowing that he or she is receiving a long-acting formulation, which can help prevent a psychotic episode that someone might have from snorting cocaine or using amphetamine or smoking a lot of marijuana.

So I don't think it's something that we should avoid when someone is at risk for abusing those drugs. I'm more comfortable if they're getting an LAI. And there are some studies which have, usually when we do clinical trials, we try to exclude people who are abusing substances because it complicates the evaluation. There have been a few trials that have utilized long-acting injectable medicines in people who have been using substances and turns out that the effects are better. And so I feel more comfortable as a physician knowing that my patient has some protection from the undesirable possible effects of these drugs of abuse.

Maye Jepson:

Dr. Kane, I appreciate you saying that because with my work with parents, I get so many parents who are concerned that, and they're usually, they put it this way, "My son is," or, "My daughter is taking an LAI," or, "She's taking an oral medication and she's smoking marijuana and she's drinking a lot of alcohol." And they have been told that the drugs or the alcohol can dilute the effect of the LAI or the oral medication. Could you speak to that?

John M Kane:

Well, I didn't emphasize this in my remarks a minute ago, but we really want to help people try to reduce the risk associated with alcohol, and substance use, and smoking as well. These are all things that we want to try to eliminate if we can. I'm not saying that no one should ever have a drink, but we have to be careful not to use these things excessively.

And also I've had patients who would say, "Doc, I stopped my medicine because I wanted to get stoned. And I thought the medicine would interfere with that." And so we don't want that to happen. We want to make sure that someone's getting their medicine. So I think working with your medical team, I think they have to evaluate what are the risks of various combinations of medicine? If someone's drinking excessively, yes, that's an enormous risk. Smoking in some cases can affect the blood level of certain drugs. We need to think about all of these things when we are managing medicine.

Christine Crawford:

Thank you. Thank you so much, Dr. Kane. Jason, there are so many questions that have been coming through, talking about individuals who really struggle to accept their diagnosis, whether it's schizophrenia or any other condition. And I'm seeing so many questions coming from loved ones who are trying to get their loved one to accept the diagnosis and to accept treatment, but to hear how accepting you were has been very helpful for folks on the call. So anything that you can share with people on the call around accepting the diagnosis, and strategies or approaches that families can use when their loved one isn't accepting the diagnosis?

Jason Jepson:

Yeah. First person accounts out there. And I'm not saying if the loved one sees these accounts of schizophrenia about the delusions, the voices, the racing thoughts, the voices, maybe they think, maybe I do have this. And if you can say, most of it would be taken care of if you take medications. I had to hit bottom for me to get help. I'm not even going to lie. I had to hit bottom. And it could have been the worst day of my life, but it turned out to be one of the best days of my life because I realized if whatever's going on in here, I'm going to get help. The police came, mom and dad were in fear of their life, and it was their only option for me at the time. And I thanked them still for doing that. It must have been hard to do that to your kid.

But yeah, just do both education. Maybe you can do it together online. "Oh, did you read this?" And I really think, what do you want me to read? But if they see some, if they're comparing what they go through and what somebody with help was going through, they may try to get help that way.

Maye Jepson:

Jason and I have been involved in the NAMI CIT Crisis Intervention Team training. And I would, if I knew, had known then what I know now, I think I would have contacted the police department in our county, and I would have made them aware that our son had a mental illness that he was not accepting. And he might be in some danger if he was out driving or something, but I would let the police know that there was an issue with him. Especially if you feel like there could be some violence involved, if the person is acting out in a way where they could hurt themselves.

Many, many police forces, especially in larger cities now have a trained team of people who know how, police officers, first responders, who know how to de-escalate a situation rather than making it worse. And so I would encourage anyone who is in crisis right now with their loved one to find out what is available in your community that you could use for help.

Jason Jepson:

The police put me in handcuffs and they treated me professionally, respectfully. Maybe it helped that I was a veteran too. But I'm glad my mom and dad made that option. I'm glad they decided to do that.

Christine Crawford:

Yeah.

Jason Jepson:

That's how I see that now.

Christine Crawford:

Yes. Yeah. And I just love Maye sharing that recommendation because that's something that a parent can do when they are oftentimes in a position in which they don't know what to do. So this is something that's actionable, and I really appreciated that you share that practical guidance and recommendation. And I imagine a lot of people are going to take those steps after this call.

Maye Jepson:

And if I could just, I just want to do one more plug for NAMI. There are many, many support groups that NAMI has that will address many of these issues. If you go on the NAMI website, N-A-M-I .com-

Jason Jepson:

.org?

Maye Jepson:

... you will find many groups.

Christine Crawford:

.org.

Maye Jepson:

.org, right. And you will find many different groups that you can be a part of. So much information is there. You'll find information about LAIs. You'll find information about groups that you can be a part of as a loved one. Ways to address different issues that you may have. But nami.org, yes. But go there. And that's a wonderful wealth of information that will help you.

Christine Crawford:

And my final question, and this is for you and Maye, what really resonated with a lot of folks on the call was how you communicated to other folks in your community about what was going on with Jason. And some people have a concern that if they have a loved one who's not accepting of their diagnosis, that if they were to go and then communicate to other people what's been going on, that could be viewed as an invasion of privacy for the person who is experiencing these symptoms. So can you talk a little bit about a caregiver or loved one can receive the support while at the same time being respectful of the person's privacy?

Maye Jepson:

Absolutely. And that is so important. And for those of you who ask that question, you are absolutely right. You do not want to do anything that will invade the privacy of your loved one. And if you're talking about someone who's over the age of 18, then you definitely want to have their permission before you do something like this. I sent this as an actual, an email to some people that we were close friends with to let them know because they knew Jason already and they knew that there was a problem when he came home from the Army. And so Jason knew that we were sending that letter out. And again, it was in an effort to fight the stigma, and we got nothing but the most support from our friends, from our church friends, from our family members who responded. They were glad to know what was going on and wanted to know how they could help.

And of course, the best way you can help is by treating this loved one as the way you've always treated them, as someone that you care about. And give them the support that they need during this time. So yes, I understand that concern. I would never, ever invade Jason's privacy. Jason and I decided early on that we wanted this to be something that our family used to help other people. And so we have done that over 20 years now. We have used our family situation to try to help others. There have been many times when we were not able, Jason was not able to do that and we did not. But the good things that have happened in his life and helping other people to know that there is hope, that's what we want to do. We want to continue to do that.

Christine Crawford:

Fantastic. Fantastic. Round of applause for these amazing panelists. It's a shame that you can't hear just how appreciative everyone is on this call. And we've received so many positive comments about all of this. So thank you. Thank you so much. If you like this, ask the expert. Well, we have plenty of others that are scheduled for the near future. So our next one is October 9th. New perspectives on Lithium, and that will be presented by Dr. Jonathan Meyer. And then on Thursday, November 20th, we have Mental Health in Rural Communities with Chuck Strand. Next slide.

Also, just wanting to put in a plug for some additional resources that could be helpful for you or your family members. And that's the two books that have been published by NAMI, so there's You Are Not Alone, that reflects more of the adult mental health journey, caregivers of adult children. And then there's You Are Not Alone for Parents and Caregivers. And this focuses on parents and caregivers of young kids and teenagers, and provides a guide for how to support their youth's mental health. Next slide.

And we want to thank our incredible sponsors who you see on this slide. And we really appreciate their ongoing support of this series because it just helps so many people. So we really want to thank our supporters. Next slide.

And remember, you are not alone. And I hope that you found the content in this webinar to be helpful. It's not meant to provide medical advice, but it's really just to help provide you with information. And this is only possible because of all the volunteers that we have. So if you want to learn more about NAMI or ways in which you can support some of our programs, we ask that you can consider donating at nami.org/donate.

Thanks for joining. I hope that you all have a great rest of the day, and thank you so much to our panelists. Thank you.