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Speaker 2: Welcome to a recap of our latest third Thursday webinar. Hear directly from expert panelists as they discuss Parkinson's research and answer your questions about living with the disease. Join us live next time by registering for an upcoming webinar at michaeljfox.org.

Kelsey Lewis: Good afternoon or good morning, even good night, wherever you are in the world. I'm Kelsey Lewis, senior philanthropy relationship manager at The Michael J. Fox Foundation. Thank you for being here with me and our expert panelists as we discuss what can be a difficult, uncomfortable, at times scary subject to talk about and navigate. For those very reasons, a topic that is not talked about enough, Parkinson's related hallucinations and delusions.

My father was diagnosed with Parkinson's 17 years ago and in the last three to four years has experienced these symptoms. So it's a subject close to my heart and what I am so grateful to be discussing here today with our wonderful panelists. Hallucinations and delusions are a symptom that can happen in some people living with Parkinson's, they won't happen to everyone, and not everyone who experienced them is bothered by them. But they can occur, and today we'll be talking about why they happen and what options exist to manage them. We've got a lot to discuss, so let's get started. Let me first introduce our incredible panelists here today. First, Ava Butler is an organizational development consultant and leadership coach. She was also wife and care partner to Richard Butler who lived with Parkinson's disease and Lewy Body dementia, and wrote a book about her experience called Parkinson's, A love story with Dementia for dessert. Thanks for joining us Ava.

Ava Butler: It's my pleasure and honor. Thank you.

Kelsey Lewis: Michael Fitts is a retired assistant dean at the University of Alabama Birmingham. He was diagnosed with Parkinson's disease in 2011 and is a member of The Michael J. Fox Foundation's Patient Council. Welcome, Michael. Good to see you.

Michael Fitts: Thank you. Good to see you as well. Thanks for having me.

Kelsey Lewis: And finally, we have Dr. Katherine Amodeo, a movement disorder specialist at MidHudson Regional Hospital and an Edmond J. Safra fellow class of 2019. To build a network of movement disorder clinician researchers across the globe, The Michael J. Fox Foundation in partnership with the Edmond J. Safra Foundation, developed the Edmond J. Safra Fellowship and Movement Disorders. Katherine Amodeo, thank you for being here.

Katherine Amodeo,MD: Thank you so much for having me. It's such a pleasure to be with this amazing group of panelists.

Kelsey Lewis: We've got a good group here today. Very excited. All right, well I think we should just go ahead and get into it. We've got a lot to discuss. We have a lot of questions about this topic and I'd love to begin the discussion with you, Dr. Amodeo. Could you level set with some definitions? What is a Parkinson's-related hallucination and how does it differ from a delusion?

Katherine Amodeo,MD: Yes. Hallucinations involve false perception, so seeing, hearing, feeling things that are not really there. It can be well-formed hallucinations or well-formed voices. They're typically visual, but they can be, as I said, tactile, so sensory, feeling something that's not there. They can be auditory or hearing something that's not there. It's different than a delusion. A delusion is a false belief, but firm false belief. So that individual believes that to be true. Those are less common, but they can occur.

Kelsey Lewis: Awesome. Thank you so much for making that distinction. Ava, I'd love if you could tell us a little bit about your husband's experience and your experience with these.

Ava Butler: Thank you for that. With Richard, I think his delusions started before the hallucinations, and his were always very fear-based. Delusions that people were after him, he got involved in a scam and he was going to end up in prison, or things like that. Then the hallucinations were mostly things he would see and hear as opposed to touching. In his case, also pretty fear-based. Not as I say, not the nice 1960s kind of hallucinations. In his case, they were always about things turning into other things, like commandos were in the trees or the totem pole had a village of people living in it, or the chairs by the pool were people getting married, or there was a band playing outside in the courtyard where the chairs and the trees were. So things like that.

Kelsey Lewis: Okay. As I said, my dad's been experiencing hallucinations, delusions for the last three to four years, and it's similar where it started very benign. He would see people in the room and he would ask my mom, his wife and primary care partner, "Do you see that? Do you see that person?" So he was able to know, "I don't think this is real." But then also after unfortunately a hospital stay, which I know Dr. Amodeo will get into a little bit later on, that became very real for him and very scary as well. Michael, I'd love to turn to what you have experienced because it's quite different than Richard's experience and my dad's experience.

Michael Fitts: Well, yes, it was definitely different. I would see and hear some things. The most common one that I used to have is, I would be in my bed asleep and it sounded like somebody was breaking into my townhouse. I could actually hear them come up the stairs and it was really, really terrifying. It was going on for quite a while until I spoke to my opposition and we got it figured out.

Kelsey Lewis: I know we'll talk about this a little later on, but Michael, yours were due to a medication that you were taking, right?

Michael Fitts: Absolutely. Unfortunately, I don't remember the name of the medic, I probably have pushed it back in my mind.

Kelsey Lewis: Yeah, don't blame you. Dr. Amodeo, it sounds like these hallucinations and delusions, they don't have to happen together. Is that common? Do you hear that quite a bit or?

Katherine Amodeo,MD: Yes. It can be so variable. It can vary from person to person. As you already said too, not everyone with Parkinson's will develop these, but we are learning more and more about how common they are and perhaps even from early on in the disease, perhaps provoked, which we're going to talk about. But they can vary from, we call it minor phenomenon, so feeling like something's passing by and looking and nothing's there, to a more well-formed hallucination, which could be auditory, visual, even a false, a sense of smelling something that's not there, so olfactory. And yes, they sometimes can co-occur with a delusion, but not always. Sometimes somebody doesn't really have hallucinations, but they have delusions. The delusions tend to be of a paranoid theme, most commonly about a spouse, either infidelity or financial. But again, it can really vary. It can vary. We're learning more and more about this because it can just be so heterogeneous and its presentation differ from person to person.

Kelsey Lewis: Dr. Amodeo, what are the precursors to hallucinations or delusions, or what are those warning signs to look out for, or are there?

Katherine Amodeo,MD: That's where I think that's why this discussion is so important. I think you may see them coming, you may not. Meaning in your loved one, you may start to observe things that make you question it, your loved one affected with Parkinson's, and these delusions and hallucinations may talk to you about them. But sometimes we don't hear about them, and it's not until maybe a discussion is brought up by your physician, which we're trying to encourage more to as far as bringing that up. Are you seeing things or hearing things that others don't?

Sometimes that's the first time that a care partner is hearing about them. They're like, "Wow, we didn't know you were experiencing this." It can vary in terms of how it's presenting, but also in terms of insightfulness. So some persons impacted are actually very insightful that these aren't real, so they may or may not talk about them because they know, "Oh, that's not real, I'm just going to ignore that." But some people are not as insightful, so that's where it can really pair into your reality as well, because it's so real for them. I think we're going to talk more about triggers in a little bit.

Kelsey Lewis:]I think you bring up a good point of, with someone experiencing this, that their care partner, their loved one might not know about. Michael and Ava, I'd love to go to that. What makes this topic difficult to talk about. I'm happy to talk about that as well. But Michael, I'd love to start with you. What makes this topic difficult to talk about in the first place?

Michael Fitts: Just really in the first place, Parkinson's in general can be kind of challenging to deal with, and you're already going through this as far as motor symptoms. Then I know admittedly a lot of people have cognitive issues as well, which I did too. But for lack of a better term, it's really embarrassing and you really don't want to necessarily talk about it to anybody because it's already bad enough as it is. Then that's been a particular fear of mine, to think that this particular issue could get

worse. But thankfully we figured out what was going on and we could address it and it hasn't happened since, so I'm really happy about that.

Kelsey Lewis: Yeah, me too. Very happy for you. Ava.

Ava Butler: For us, we decided very early on that we were going to be completely transparent about Richards Parkinsons and both the physical and the emotional, the hallucinations, all that kind of stuff. We were open to talking with people about that, not strangers on the street or anything, but people in our spheres, our families of course, and friends. Especially when people were coming over to give them an update of what they could expect with Richard's physical and cognitive issues.

One thing that, going back to the question of how do you know. For Richard, his hallucinations were extremely real. It was no different than us having this conversation. It was not like he could differentiate. The way I could tell is that by the way he was talking, but he'd start to look past me. So if there's somebody else in the room and you're looking past them, he'd be looking behind me, but there was nobody there. I didn't see anybody there, but he did. That was always my prompt that something was going on. Then I would say, "Well, what are you seeing Richard? Tell me. What's going on?" Even though I couldn't see it, well, I learned the hard way to ask questions with curiosity and support him in whatever way I could.

Kelsey Lewis: Yeah, absolutely. We'll get into more of that conversation later on for sure. I'd love to turn now back to Dr. Amodeo and the causes of hallucinations and delusions. What are those causes of hallucinations and delusions?

Katherine Amodeo,MD: Firstly, they may be just part of the disease itself. Like I said, not everyone will experience them, but we do think they can be an inherent feature of the disease, so due to the disease itself and the different neurotransmitters involved and so forth. So it can be a feature of the disease itself, they may also be triggered, and medications is an important trigger to talk about. The medications that we use to treat the motor features, the dopaminergic therapies, Amantadine and so forth. Any of those medicines that we use to treat the motor features may contribute to hallucinations, so that's something that we're always checking in on and we should be asking about, and you should be letting us know if you're experiencing this. If there was a new medicine added or perhaps a dosage was adjusted, this could be a side effect. But additionally other medicines that you may be started on, we know that some cholinergics for bladder dysfunction, if you had a surgery and you were put on pain medicines, those can be a trigger. Again, on the topic of getting a procedure done, anesthetics may be a trigger.

Infection is another important consideration. When we hear about acute hallucinations that you weren't having any and all of a sudden now you are, something we want to think about is what else is going on. An infection, a urinary tract infection, that [inaudible 00:12:52] infusion, hallucinations may actually be the only feature of it. That's something to keep in mind, as we get older and as we have a disease that's like this, like Parkinson's, you may not mount the same response of an infection that you may have earlier in your life

with such as a fever or pain. So sometimes this may be the way that we know we're alerted to something going on. I think we've talked about situations where maybe you're visiting a loved one or you flew on a plane to visit someone or you're in a hospital setting. That change of environment, the change in the clock where you're getting vitals taken in the middle of the night, those kinds of things can actually trigger these as well. Those are important considerations as we're trying to determine what's going on.

Kelsey Lewis: Listening to you, Dr. Amodeo, my poor dad, he checks all those boxes. He had all of those unfortunately, due to Parkinson's themselves, due to UTIs, due to a hospital stay. That's something I know we've talked about and I'd love to talk a little bit about, is hospital psychosis or delirium, and how that can also trigger hallucinations and delusions in people with Parkinson's and, am I correct, people without as well? It's something that can happen. If you want to talk to that just a little bit, I think that would be great.

Katherine Amodeo,MD: So you bring up a good point in that honestly, everyone is at risk for delirium. Delirium is a change in your mental status with confusion fluctuations where there's moments of being more alert and moments of more sleepy and hard to arouse. That's what we mean by delirium, it's an acute change. That's the difference between say a more progressive established process like dementia, delirium is this acute change in your thinking and cognition and there's usually a trigger. You were right, anyone is at risk for this and common triggers are infection. We even see this in kids who have a high fever, so anybody could experience delirium, it's just more common in our patients with this disease or other neurodegenerative diseases.

So you said hospital delirium, that we will also have ICU delirium. Again, a situation where day and night is not so clear, because there's always vitals every two hours and things like that. That change in our clock, we really weren't meant to be awake around the clock, we were meant to sleep at night and be up during the day. Which is another important trigger. When I hear about people having changes in their sleep patterns and so forth, that's another potential trigger for confusion and hallucinations.

Kelsey Lewis: That was a term when my dad has been in the hospital a few times. The first time was just a term that they threw out and we had no idea what they were talking about, the medical staff, and they seemed to think we should know what that was, because for them it's very common, they do see it. And for us, it was beyond scary for us and my dad to deal with and try to figure out. I think that's something we've talked about too, is making sure that that's more talked about in the medical community and in our community as well. Michael, I'd love to turn to you. Since your hallucinations were caused by medication, what happened when you changed the medication?

Michael Fitts: Well, what we had to do, my physician, we had to make some adjustments to the medication and we lowered it. Actually, after we lowered the dosage, it cleared up. But interestingly enough, there's somebody else in my family that has hallucinations as well, so I was able to talk to her about it and we actually kind of helped each other because it made me feel better that somebody else could really

relate and understand. I don't want her to have hallucinations like that, one little brief little incident really, really helped us both.

Kelsey Lewis: And to be able to talk about it and to know that that might happen and you're not alone. I think that was something, when my dad experienced that, we were shocked. We didn't know what was happening. I'm so grateful again that we had the space to talk about this and that you talk to your family about it too. These conversations are so needed in many different spaces. With that kind of along those lines, Dr. Amodeo, will medication related to hallucinations and delusions, do they normally go away with medication changes?

Katherine Amodeo,MD: As Michael said, which thank you much for sharing your story. Yes, if there's a clear provoking cause, and so we can say, "Oh, with that increase in medicine, that's when this happened. Let's try coming back down on it." Most of the time, yes, that can be helpful. But keep in mind, like I said, it can also just be a part of this disease, so sometimes we try to make a change, we try to identify a trigger that may not actually be the trigger, is what I'm saying, so it may actually just be a part of the disease. But certainly it's always, that's why always take a look at the medicines, what's new, what was a change, and see if we can help.

Kelsey Lewis: Yeah, absolutely. Ava, were Richard's doctors able to pinpoint the cause of his hallucinations and delusions?

Ava Butler: His doctors told me that hallucinations were not part of Parkinson's. That was 10 years ago and I pray that's not the case now, but I was the one informing them. There's a lot of education yet to be had. Most of what I learned was through the School of Hard Knocks. I will say that shortly after Richard got diagnosed with Parkinson's, he had knee replacement surgery and the anesthesia, that was the triggering point for when his hallucinations got worse and they never got better.

I think with most people, they go to the doctor, they have anesthesia, and you get over it. You're foggy for a while, but you get over it. In Richard's case, unfortunately that was not true. I learned years later that it's a really good idea, in fact, I would say it's imperative, to tell your doctor who's doing a surgery that you've got Parkinson's and dementia or hallucinations and be sure that the anesthesiologist understands that. I believe they can change or modify things, because people with Parkinson's have a higher susceptibility or impact on anesthesia than some other people. Other,

Kelsey Lewis: Yeah. Dr. Amodeo, will you confirm that for us?

Katherine Amodeo,MD: Absolutely. Ava, thank you so much. Yes, I've even been in discussion with some of my colleagues in surgery, neurosurgery and so forth, knowing this and we have come a long way, thanks goodness, they'll often make a change in the level of sedation or the type of anesthetic used, and it does help.

Kelsey Lewis: Ava, I think you also bring up such a good point, that you were an expert in Richard. You knew what was happening to him, you knew what was normal, you knew what was not. My mom is the same, she's the expert in my dad. To those in

the medical community, sometimes I feel like that's not as respected as it should be or listened to, because they see this every day in and out. But that's just something, I would say, that needs to be respected. You are in this, you are living this just right beside them and you're an expert in how they're doing. When this happens, it's something that's so scary for you and your partner and your family as a whole.

Ava Butler: Don't be afraid of the doctors. If doctors we're dismissive of you, don't back down. You've got to be an advocate. Be strong in your... Respectful of course, but don't let people intimidate you or stop you from doing what you need to do, to your own advocate or the advocates for the one that you love.

Katherine Amodeo,MD: I just want to just point out, it's because of advocates like Ava and that we've learned more about this. REM behavior disorder is a very important example of something that we didn't know about until we started to hear about, "Oh, this has been going on for years, 20 years before you came to see..." You know what I mean? And we learned it was an important prodrome. So yes, don't be afraid. We're all partners in this together.

Kelsey Lewis: Honestly, Dr. Amodeo, thank you for what you do and for saying that, because it means so much to those care partners that are listening to this and those with Parkinson's that you do that. My dad's movement disorder specialist is a member of our family, so we appreciate her advocating for us as well.

Okay, so let's go on to treating hallucinations and delusions. Ava, how did you and Richard navigate having these conversations with your doctor?

Ava Butler: Well, we were very open about it and learning together really, because the neurologists didn't know more than we did. But having open and honest conversations and proactive, I think it's good to agree in my case with Richard what we're going to talk about and who's going to say what, so he would be positioned. He never felt embarrassed by this and neither did I. I wish more people treated Parkinson's and hallucinations and delusions like we treat heart attacks or strokes or cancer. It's just something that happens, there's nothing to be embarrassed about, it's just something that's happening in our bodies. Then be sure to, like I said, prepare for the meeting. Make sure that, tell your doctor what you want to cover because they're all busy, and then make sure you've got a follow-up plan.

Kelsey Lewis: You bring up, just kind of a side note, I work with a great couple here at the foundation who, if you have a care partner that goes with you to these appointments, they actually leading up to his movement disorder specialist appointment, they make lists and they don't show each other those lists until they're in the room together. Things they want to talk to the movement disorder specialist about that they both noticed, and then they bring both of their lists into the room to discuss, which I thought was such a great way to do that. Again, if you're lucky enough to have that loved one or care partner with you.

Dr. Amodeo, how can a person most successfully start this conversation? What about people living with PD aren't experiencing hallucinations or delusions, why is it important to talk about it early on?

Katherine Amodeo,MD: Yeah, excellent. A couple of things. Firstly, lists are incredibly important and they make the visit just so much better in terms of we can gear it toward what you want to cover, so always encouraged. How do we start the conversation? I think it's something that, generally going to a specialist who knows about this, it's generally part of our intake. If you don't come with a big list of things, we'll generally start checking in on symptoms. Again, we've increasingly learned that non-motor features are part of Parkinson. For years we've known about the motor symptoms, the tremor and so forth, but we're learning more about the non-motor aspects. A thorough evaluation should include questions about this. Are you seeing things, hearing things that other people don't? I'll say, particularly in my newly onset patients where this is less common but may occur, I'll say, "You may not." I'm going to ask a whole bunch of questions, some things you may never experience, but because it can happen, I ask about it.

That's one thing that going through. Now, if that's not happening in your appointments, then again, that's why these discussions are so important to spread awareness that yes, maybe if you're not being asked about it, make sure you're checking in with your doctor about this, "I don't have these, but I heard about these. Can you tell me more?" I think there are commercials now when we talk about treatment, so I have been getting questions from patients who don't experience them, but asking me, "What does this mean? Will I get this?" Then we talk about it. I think it's just like Ava said, it should just be part of our discussion. As we check in on your motor features, we should be checking in on these non-motor things that may or may not happen.

Kelsey Lewis: Yeah, absolutely. As a movement disorder specialist, walk us through how a doctor thinks about treating these symptoms.

Katherine Amodeo,MD: Calling in, which it sounds like Michael's doctor was very good about this, is looking at anything provoking. When I hear about them, I'm looking through what changes were there. I'm asking them, "Would you start a new medicine with somebody? What's new? What else is going on?" Sometimes you will hear about increased urinary frequency and so forth, so then we're thinking about, maybe, "Let's check for urinary tract infection. Let's make sure we're not missing a trick that we can correct." That's first and foremost, "Is there anything we can correct? We will look to the medicines you're already on that are treating your motor features and see if maybe we just need to lower. This is happening mostly at night, so at bedtime you're getting this. Maybe let's lower and see if that helps."

When those things don't help, then we can look to other treatments. When I say this, I want to make sure we talk about pharmacologic, so meaning medication, and non-pharmacologic, meaning we don't necessarily have to start something. That's not always the right thing. If they're mild, intermittent, maybe the person is insightful to them, but maybe they're not, but when their partner reorients them or validates them, that's helpful. So validation, I think on this call we heard about therapeutic fibbing, which I love that expression, because I think it's important to

give that permission to it's okay to fib or to, I always say validate. "Yeah, I see that too. I told them to go away." I want to hear more from you guys about that. So non-pharmacologic approach is very important too as we think about treatment. But when those things aren't enough, and if the hallucinations are scary and bothersome or really impacting one's life, their peer partner's life, their safety, then we do look to medications.

This is an important talk. Because many medicines of the anti hallucination, anti-psychotic class, so psychotic is a term that includes hallucinations and delusions, so that's where that term comes from. But many of those medicines are actually not safe in our patients, because they can block dopamine, the messenger of the brain that we know to be reduced in this disease. We have to be very cautious, so we look to those of this class that are least apt or not apt at all to block dopamine. Those three, there's actually three, are Quetiapine, Clozaril and Pimavanserin or Nuplazid, it is the brand name. Quetiapine is Seroquel, if that sounds familiar. Then Clozaril or Clozapine. Those are the only three of that class of medicine that are safe.

We do use a different class of medicine as well, and for some of us, this is actually one of our first line agents, is of the Acetylcholinesterase inhibitors class. Those medicines are like Aricept or Donepezil, Rivastigmine, Exelon, if you've heard those names. They can help less in hallucinations as well and are often well tolerated, so we do have medications. Again, that's why it's so important to talk about this because if we can help lessen them and perhaps make them less frequent, less severe.

Kelsey Lewis:

I think that's a good point to share, that for some folks going on these medications, their hallucinations or delusions might not just go away, but they'll lessen. I work with another wonderful individual who we were sitting in his living room and he saw a carousel out the window and he was like, "I know it's not there, but I see it." And he said, "But I'll take this over what I was experiencing before starting medication."

I would love to transition into navigating life with hallucinations and delusions. Michael, to transition us into this section, I'd love for you to talk about what you would approach your doctor, how would you approach your doctor about this topic? Then also your loved ones. How do you stay in communications with your loved ones? What would be helpful for you, for your loved ones to ask you?

Michael Fitts:

Well, one of the things is really having somebody to go with you on the appointment. I'm a little bit different, I'm single, I live by myself, so when it comes to the appointment time, I have to go by myself. The nature of Parkinson's in general, there's things that I forget. I think that was a great idea about the list to bring. The other thing that's really, really pertinent about this point is, it seems like because our movement specialists are so busy, there's oftentimes where there's a long extended period of time before you get to see your opposition, and during all that time, you need to have a way to communicate.

One of the ways that I communicate with my care team, and it's all about a team, it's not just one person, is there's a login mechanism where you can contact

your... But anyway, that's a way to kind of communicate in between your appointments, and that's really important. Because what you don't want to do is, say your appointment is six months out, a year out, you don't want to wait six months or a year before you have a conversation with your physician about this. This is serious stuff. So as far as the family bringing them in, and I'm really challenged to do this, I'm glad that we're having this conversation, I think it would be helpful sometimes to bring somebody in that's going to get those tools and those nuggets that you might have missed.

Kelsey Lewis: Yeah, absolutely.

Michael Fitts: Patient portal, that's what it's called. Patient portal.

Kelsey Lewis: Portal. I know what you were talking about, I could see it in my mind. The patient portal.

Katherine Amodeo, MD: That's a great idea, Michael. Sometimes people will actually message me before their appointment, like, "I know we're seeing you next week, I just want to make sure we talk about these things." Because it may come to you at certain times, so I think that's a great idea.

Kelsey Lewis: And for you to already be thinking about even before their appointment and be prepared for, that's such a great tip. Absolutely.

Katherine Amodeo, MD: Yeah, I appreciate it. Yes.

Kelsey Lewis: Ava, how did you and Richard communicate about this topic?

Ava Butler: For Richard, we didn't talk about them in between episodes. For him, it was just reality. It was just like, we're having this conversation and it lasts an hour and then we do something else. There was no discussion like, "Hey, what the hell happened during that hour?" Because for him it was extremely real. For me, and I learned this the hard way, because at first I would argue with him, "No, there's nobody in the room," which is not helpful because then I became part of the. So I learned to go with it and be there and ask him questions about what he was seeing, which seemed to help him. I would write down a lot of the things that he would say, because they were profound sometimes.

So I would either just ask him what he was seeing, or if they were fear-based, which they often were, I'd say, "Well, those people aren't allowed in the house. They didn't get invited here. I'm going to ask them to leave." And I'd say, "You." And I couldn't go too fast, I had to go slow because he said, "Don't scare them." But I'd say, "All right, thank you for visiting. It's time for you to go, we've got other things to do today." I would literally open the door. These were people, in this case I'm talking about, scary people with tattoos on their teeth and things like that. I would say, "It's time for you to go. Let me escort you to the door." And I would literally walk to where they were and say, "Okay, it's time for you to go," and I'd escort them out the door. That seemed to help. Just be there with him. I

think the most important thing is to be present, get your own voice out of it, and just be there and be helpful.

Kelsey Lewis:

That is such great advice, Ava. I would like to acknowledge, and I think you would as well, that we're saying this and knowing how hard that is as a loved one, as a daughter, as a wife, to transition to that. So those that are out there that are dealing with this, and this is new, be kind to yourself, be kind to yourself if you're a person with Parkinson's. This is such an, as we've talked about, uncomfortable topic to navigate and to deal with. If at the beginning we did the same thing with my dad when he was starting to experience these more scary, very real delusions, his were, somebody was after us or someone was after him. We were like, "No, you're fine. You're fine. Nothing's wrong. No one's here. You're good." And we became part of the problem.

So we've definitely learned, exactly what you said, Ava, to start asking questions to see what he's seeing, "I don't see that, but what is it that you're seeing?" Recently we've come across a term which Dr. Amodeo brought up, a therapeutic fitting. Which I wish I could coin the phrase of who said this, and if anyone knows, please let us know. But it has helped my family so much. As many folks we're very honest with our father, and my mom is with her husband, so this tactic of therapeutic fitting is, it's okay. It's okay to be a part of the delusion or to do these things.

Recently my dad was telling me there was a lawsuit. It was in someone in D.C., we had to get to D.C. There was a lawsuit, we had to get to D.C. Everything in me wanted to say, "There's not, you're fine, you're safe." But instead, I've learned and I've said, "I've got it. I'll book the plane tickets right now. No worries, I'll take care of it." He was like, "The hotel too?" I said, "I've got the hotel. No worries. I've got you. You know I've got you, I've got you." That calmed him down and he went on and ate his dinner.

Ava Butler:

If I may add a couple of things, it is a new skill. We're learning new skills. Just like you're learning how to a new language or learning how to cook or something, we're learning. Like you said, Kelsey, be kind to yourself if you're the care partner or the person going through this. I would add a couple of other things, one is that if I asked Richard to look at me. I said, "Look at my eyes for a second," it seemed to ground him. The other thing I would do, and I love what you said, "I've got it. I'm booking the tickets," remind the person we are safe and secure, "We are safe now. It felt scary, but those people are gone or they look scary, but they're really on our side." Whatever it is, to just don't let it escalate.

Kelsey Lewis:

Yeah, absolutely. Dr. Amodeo, a little to you, circling back, I know we talked about therapeutic. Are there other things that you've heard from your patients who you would recommend in these situations?

Katherine Amodeo,MD:

Excellent. You're all doing amazing and I love, be kind to yourself. But yes, there are other things. Validation is one, just like you said, "I see them. I got this, I took care of it. I called mom, she's fine. Everything's okay." But also distractions. Sometimes when validation isn't going the right way. I would say too, just like you guys said, you're experts in your loved one, so you're going to see what

works. Everybody's different, some people respond to validation, some people respond to orientation. Which is, "No, that person's not there. Oh, nope, that's a hallucination." Some people respond to that, some people don't.

I just had somebody tell me, "I don't want you to lie to me. I want you to tell me." Everybody's different, you're going to see what works. You may even ask them, "I've done this, "If this happens, how would you want me to respond?" That may or may not be appropriate, depending on your level. But sometimes they'll tell you, "I want you to tell me the truth. I want you to..." Or, "For me it's so real, so I'd actually rather you go with it." They may be able to tell you that.

Distraction is an important thing. I've been in a situation helping a loved one manage this, or in the hospital where it's happening, and we will distract, "Tell me about your favorite room in your house." If I'm on the phone trying to de-escalate somebody, "Tell me about your favorite room in the house." It's amazing how you can kind of get them, "Well, I love our library," and they might have to, "Tell me more about it." Music therapy, creating a soothing, calm environment. I often will say, music from your heyday, so your wedding music, the ones that will invoke pleasant memories can actually be very helpful. The important thing why I said creating a calm environment, which you don't want to do is, if it's scary or fear-based as we were talking about, you don't want to escalate. You don't want to say, "No, this isn't true," then that can, like you said, you become part of the trigger in a way where it's scary like, "You're not on my side." So you want to stay calm, talk with a soft voice and emphasize safety, emphasize you're safe. That's the important thing.

Kelsey Lewis:

Also, when you were talking about the person, you don't know how they respond. You've got to learn your person, you've got to learn what they're doing and what works for them. I love the thought of asking them before. As we've talked about, some people who were experiencing hallucinations or delusions, they will know that the hallucinations aren't real, but sometimes they don't, so it very much varies.

Michael, I would love to turn the conversation to you and I'd like to talk more about how would you like someone to approach you? Then also as you don't have a care partner in the home, do you have other resources that can help you?

Michael Fitts:

You should have some type of company, even if they're not a relative, a good friend that understands what you're dealing with and it's genuinely concerned, that's one thing that I would do. As far as how to communicate with me, I like for people to be straight up and just don't beat around the bush, just tell me what you need to tell me. But at the same time, find some type of balance. You want people to be sensitive to your needs because it can be a little overwhelming.

I found out that I really get more information when I go to the physician, to the doctor's office. Because one thing that's discouraging as far as communication, is some of the pharmaceutical commercials, they'll list all of these side effects or whatever, which is fine, but it can be overwhelming. If they could find some type of middle ground maybe to communicate that stuff, it can just really be scary. They'll end the list of comments or side effects with death. And it's like, "Wow,

did you have to really drop the bomb on me like that?" That's how I would prefer to be communicated with, so I hope that helps.

Kelsey Lewis: It so helps. I also appreciate you brought up, it sounds like you're lucky enough to have a lot of people in your life that love you, and our family does too. I know everyone wants to help and sometimes they want to commiserate. They're like, "This is so hard." And it's like, "I know it's hard. I don't need to hear that too from you." What would you say to those loved ones that just want to help? What do you say to those people?

Michael Fitts: It depends on who it is. You know the people in your family and who's got strengths in one thing and maybe not so much in another. You have to pick your person, I think somebody said earlier, in order to get your help from that. Because depending on who it is, I think you might receive it better from one person necessarily than another, so it could be something. The thought that I had before too is, as far as the physicians are concerned, you don't want to drop the bomb on everybody and have, like I said, this long-drawn-out list of side effects, let people know that this happens in some people, it doesn't happen at all. All medications have some type of side effect or what have you, but that doesn't mean that you're going to have a side effect and have all of that come down. It's nice to know, but then at the same time, you have to balance it out.

Kelsey Lewis: Yeah, absolutely. Well, I think our conversation has been absolutely incredible. I can't believe we're closing in a little bit, but I think it's time for our Q&A portion.

We have a great first question and I'm so glad someone from the audience asked this. "My mother also has mild to moderate dementia. How can I tell the difference between dementia symptoms and delusions and more generally, what link is there, if any, between cognitive changes and hallucinations and delusions?" Dr. Amodeo, I'll go to you first on that one.

Katherine Amodeo,MD: Sure. Cognitive impairment, cognitive changes, so changes in our thinking, our memory, our processing, our visual, spatial, the way we see the world around us, may be a feature of Parkinson's, may not. Not everyone with Parkinson's will experience cognitive changes. When we think about more progression in cognitive impairment, where there's more global involvement across different domains of thinking, so memory, language, visual, spatial, executive function planning, that's when we use the term dementia. Dementia is more severe cognitive changes, but some people may have mild cognitive changes, maybe just trouble with one domain, so attention or focus things. So it can really vary from person to person. Again, I keep saying vary, but that's just so true. This disease things just are different from person to person, so you may experience cognitive changes, you may not.

Cognitive impairment may or may not be present with hallucinations. That's something we've recently, again, I think that's more a better understanding, we've often thought about hallucinations and delusions and cognitive impairment as features of disease progression, so occurring as the disease worsens. Often we've thought about delusions and hallucinations occurring more in those who have cognitive impairment, those who have dementia. Certainly that is where it's more

common. It is more common in later stages, it is more common in those with cognitive impairment or dementia, more severe kind of impairment. But it doesn't have to be there. You don't have to have cognitive changes to have hallucinations and delusions. It may be triggered by a medication or infection, and again, it doesn't mean that you have cognitive impairment.

Then so when we talk about the difference between delirium and cognitive impairment or more severe dementia, again, the key difference there is cognitive impairment and dementia is not something that happens overnight, it's something that is gradually progressive over time and persistent. Delirium is something that there's this acute change where somebody maybe looks like they have dementia, but it happens suddenly. It happened overnight and generally there's a trigger, so an infection, medication change. Now sometimes we hear, mom or dad or my husband or wife, "They were fine until this happened." I think we heard Ava shared that with us, that her husband didn't have hallucinations until they had a surgery. We can hear that, so why is that? It just may be that there was that stressor just unmasked what was going on. Meaning likely that things were progressing, and then that stressor to the body, whether it physical, emotional, it just kind of unmasked it. It was almost like the straw that just caused a blooming of the symptoms. So we do see that too.

Kelsey Lewis:

I'm very glad that you brought that up, because with Ava too and myself, my dad, now looking back, were we seeing some signs of some dementia, some cognitive issues, otherwise? Yes. But he took falls that landed him in the hospital, and it was just a sudden cognitive decline. It was so scary. Now that I work in the field, and I talk to so many folks that unfortunately have this experience. But I'll also say, when you're going through it as a family, Parkinson's can be very isolating in general for the person going through it and their families. But this was just next level, was you just felt like, "Oh my gosh, what is happening? What do you do?" And no one really had the answers for us either, or also expected us to just know this was common. What would you say to those families who might be experiencing this?

Katherine Amodeo,MD:

Bringing back that whole, be kind to yourself. How would you have known this was coming unless it happened? We're learning about this together and we're going to talk. Then don't be afraid to talk about it, ask questions. We're going to work through it. Certainly your provider should be looking for triggers if possible, but then also understanding and reassuring that yes, this is also part of the course and we're going to again, be your partner in this new part.

Ava Butler:

I just wanted to add, and I'll be brief, because I know we got a lot to do. For Richard, cognitive decline was bundled in with this. Executive functioning, which sounds big, but it's really just the steps, like all the steps to load the clothes into the clothes washing machine or wash the dishes or dress yourself, all those things, or speak clearly, those were all part of it for Richard. Like we've all said, it's different for other people, but for me it was just a bundled set.

Kelsey Lewis:

Bundled package. I'd love to move on to our next question, because this is actually one I have as well. There are so many questions around RBD sleep disruptions and how do those correlate to hallucinations and delusions. Dr.

Amodeo, I'm going to go to you first. Will you also just really quickly remind us what RBD is?

Katherine Amodeo,MD: RBD is REM behavior disorder. When you are in your dream stages, the REM stages of sleep, which means rapid eye movement, that's when you're dreaming, those who aren't impacted by this disease or similar diseases generally is atonic, so doesn't have any tone. We're paralyzed, so for a safety perspective, if we're dreaming about running from a lion, we're not running from a lion. Now, those with Parkinson's or those at risk to develop Parkinson's, this can occur years before the onset of the motor features or cognitive features, can actually act out their dreams. So it's dream enactment, running, yelling out, punching. That's what REM behavior disorder is.

So yes, so sometimes that can be misinterpreted as, "My loved one's experiencing something," but maybe they're just dreaming. Then I'll ask, "Does this happen? Are they seeing things or hearing things that aren't in sleep?" That's the other thing is, that those with Parkinson's, we've looked at this too, can have very vivid dreams, realistic dreams. Often have a nightmarish quality, they actually looked at this, they're more likely to be nightmarish than a... And sometimes they may carry through when you wake up. So if somebody wakes up and they're still very bothered by this dream and thought it was real. Again, it's working through that, "Was this a dream? Was this a delusion or hallucination?" That's when I, "Is it just happening during sleep or when they wake up from sleep?" Those kinds of things.

Kelsey Lewis: We've heard the term active dreaming, is that a part of this? Because my dad does that a lot, he'll be kind of falling asleep, reaching for thing. We've learned that for just active dreaming. Would you say this as along those lines?

Katherine Amodeo, MD: Yep. We'll say, dream enactment, acting out your dreams, that's what we mean, that is that REM behavior disorder, yes.

Kelsey Lewis: All right, last question to wrap us up. I can't believe it. For Michael, if you are not experiencing hallucinations and delusions, how do you think about talking to your doctor about this symptom now, to be proactive?

Michael Fitts: I'm willing to go to her and just really reach out to her and ask her, "What's going on with this? Because I'm starting to hear a lot of it. I'm starting to read articles about it. I'm starting to see commercials about it," and that kind of thing. And just see what kind of response that I can get from that. Because I'm sure she probably gets 50 million questions, but she's always kind and answers all my questions for me. That's how I would do it.

Kelsey Lewis: Yeah, I think that's such a great tip. Ava, anything else or Dr. Amodeo, with our last couple of seconds that you want to make sure our incredible audience today knows?

Ava Butler: I would just say I am so grateful that we're having this conversation and learning together and being open about it. It's a journey. Like I said before, be kind to

yourself. It's like learning a new language, if you're the person or the caregiver. Just treat it as respectfully and positively as you can.

Katherine Amodeo,MD: I would echo that. That was beautiful. Exactly. Well said.

Kelsey Lewis: I completely agree. As I was looking through the Q&A questions, I was shaking my head, "Yes, yes. Oh my gosh, yes." Because we've experienced this too or had questions about everything that was talked about today, so thank you so much. For those of our audience, I hope this was helpful today. You are not alone. This is something that happens and I hope this was helpful.

Thank you again for being a part of our community and for joining us today. And thanks to our panelists, you guys were so incredible. Thank you so much. We hope you found today's discussion helpful, and thank you so much and have a wonderful day.

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