

Lewy Body Life

Season 1, Episode 5: Hallucinations and Delusions? Go With the Flow

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Welcome to Lewy Body Life. Lewy Body Life helps care partners, family and friends understand and navigate the often complex and unpredictable Lewy Body Dementia journey. Here real people with real experience and real insight share essential information for caring and coping. We hope our podcast series will help you realize that you're not alone and that there are strategies and resources that can aid you in your LBD journey. Now let's go to your co-hosts Ann Brucciani Lyon, Paula Rice Bieber and Linda Olsen Engel.

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Ann: Hello and welcome, I'm Ann Brucciani Lyon.

Paula: I'm Paula Rice Bieber.

Linda: And I'm Linda Olsen Engel.

Ann: We're delighted to have you join us for today's episode **Hallucinations and Delusions? Go With the Flow**.

Paula: Now seems like a good time to remind our listeners that we're not professionals and the information we are sharing here is not intended to replace seeking the appropriate medical, legal or tax advice for your specific situation.

Linda: Yes, Paula, thanks for doing that. We're here to help raise awareness and understanding about LBD and hope that the information we share will help guide you, our listeners, to the resources you need.

Ann: We know that you've been eager for us to cover today's topic, so we're going to get right to it.

Linda: We're talking about what many people consider the most challenging aspect of caring for someone with Lewy Body dementia — hallucinations and delusions.

Ann: This is going to be a long episode because we wanted to do the topic justice. And there's a lot of information that will validate your experiences and help you respond more effectively to these situations.

Paula: It can be extremely difficult for care partners when the person they're supporting becomes obsessed with delusional thinking or is agitated and distressed while experiencing hallucinations.

Ann: Yes, those situations can — understandably — be utterly overwhelming for care partners.

Paula: Yes, it can become so overwhelming that a person with LBD can no longer be cared for at home.

Linda: But these issues aren't always dealt with very well at care residences either.

Paula: You're right, Linda. That's why it's important to learn strategies for dealing with these challenges. These strategies can help care partners alleviate distress for the person with LBD. And if care outside the home is the right decision for your situation, learning these techniques can help you assess whether the staff is knowledgeable and skilled in how they respond to and communicate with someone with LBD to de-escalate a situation.

Ann: Absolutely, Paula.

Linda: So, let's start out by defining the difference between hallucinations and delusions.

Paula: A hallucination is when a person perceives something that doesn't exist, at least not in the outside world that is shared with others. It can involve any of the five senses — sight, sound, smell, touch, or taste. The most common hallucinations involve sight, followed by sound.

Linda: So you'd call seeing a person or animal that no one else can see, a hallucination, is that right Paula?

Paula: That's correct. Or if you hear a voice or a sound that no one else can hear; that's an auditory hallucination.

Ann: So Paula, do people experience hallucinations that involve more than one of the five senses? Can they both see and hear things that aren't there?

Paula: Good question, Ann.

Linda: I recall a time my husband said he "saw" a war outside and simultaneously reported "smelling" a mixture of fire and oil. He was so upset and I felt tremendous empathy for his fear.

Paula: That's an interesting example, but I don't think that's very common from what I hear from my support group members. The people and animals they see don't make any noise, and the sounds that they hear don't usually have a visible source. For whatever reason, it's usually only one sense that is involved in a hallucination.

Ann: Thanks, Paula, that's interesting. And now that we have a better understanding of what a hallucination is, can you explain what a delusion is.

Paula: A delusion is a false belief about something, even when there's strong evidence that the belief isn't true. It's more abstract than a hallucination, which involves our senses. A delusion involves our thinking.

Linda: Ooh, great explanation, Paula!

Ann: So, if someone thinks that you're stealing from them, or that they're being spied upon by the neighbors, and there's nothing to base it on, that's a delusion?

Paula: Yeah, that's right. A delusion can also be a false explanation for why something happened, or a memory of an event that never occurred.

Ann: That makes sense. And I've been in situations where I've been given false explanations and told stories about events that never happened.

Linda: Yes, I have too, Ann.

Ann: What you just said helps me understand those experiences better.

Linda: Exactly, Ann. Or — sometimes they retell a story that happened to someone else as if it's their own story — as if the events happened to them even though they were never involved.

Paula: Yeah, delusions can be an entire conjured-up point of view about someone's place in the world. My dad, for example, thought he owned multiple businesses. He claimed he had restaurants, hotels, a wedding venue, an ice cream shop, essentially a whole town's worth of businesses.

Ann: Oh my gosh. So, Paula, let's clarify this one more time. A hallucination is a direct experience, involving the senses, like seeing people or animals, hearing voices or music that others don't perceive. While a delusion is a false belief about what's going on in the world around them.

Paula: That's right.

Linda: There were times that I thought my husband was actually in a totally different reality.

Paula: That's how they are experiencing these things, Linda. Hallucinations and delusions **are** like an alternate reality. Kind of a double-trouble! And you have to deal with that reality.

Linda: What a great way to explain this, Paula! You know, I remember entering my husband's room one time and he immediately asked if I'd seen the daily paper. He was very agitated and said not to believe anything that had been printed about us. I now realize that was more of a delusion, not a hallucination.

Paula: So he thought that some incident involving the two of you had been reported in the newspaper?

Linda: Yes and it wasn't very nice.

Paula: Wow! And yes, I do think that was a delusion. He didn't see or experience something happening, he believed that something had happened.

Linda: Right. Although, maybe he was hallucinating about the article in the newspaper!

Paula: Hallucinations can trigger delusional thinking. For example, hallucinating that there's a man in the backyard might lead someone to think they are under attack. But you can certainly have delusions without any hallucinations.

Ann: Good to know. And, now that we've explained the difference between hallucinations and delusions, let's talk about hallucinations in greater detail.

Linda: Uh huh, I think that's a good idea because it's really startling for most people when a person with LBD begins having hallucinations. And with LBD it can happen early on in the disease — long before you have a diagnosis.

Paula: Yes, Linda, It's really alarming at first, and you don't know what to make of it.

Linda: It can be a shock when your loved one *initially* sees something that you know isn't there — that you yourself don't see. Your mind just spins trying to figure out what's happening at this moment — is this a medical emergency or has your person gone crazy?

Ann: Isn't it true that oftentimes what they see doesn't make sense to them either? But because they see it, it must be real?

Paula: That's how my Dad reacted, Ann. He had a very frequent hallucination that didn't make sense to him. At night he'd look out his window and see his dad outside on a tractor, going back and forth plowing up the lawn. (My grandpa had been a farmer in North Dakota.) My Dad told me "I don't know why he's doing that in the middle of the night! Plus, he has to be at least 115 years old by now!"

So even though my grandpa had passed away long ago, my Dad was sure that was him out there on the tractor, even though it made no sense to my Dad that he'd be doing that.

Linda: What a great example, I love that.

Ann: I do too. Paula, you've mentioned that when care partners encounter challenging symptoms — like hallucinations and delusions — their first impulse is to ask about medication.

Paula: Yes, they want something to make those symptoms stop. But it's important to take the time to evaluate the situation first. Medication isn't always the answer. Sometimes sedatives and antipsychotics can make matters worse!

Ann: Why is that?

Paula: Persons with LBD may be very sensitive to those types of medications. They can either over-respond and become dangerously sedated and comatose, or the drug can have the opposite effect and increase agitation and delirium. They can even make the hallucinations and delusions worse!

Linda: That's for sure! After taking what was most likely a sedative prior to his MRI, my husband woke up from a nap and leaped up trying to get bugs off the ceiling. This was his very first hallucination and I was so flabbergasted, I was speechless. THEN he approached me and exclaimed: "You've got green lightning coming out of your eyes."

Ann: Ugh, I just can't imagine what that was like, Linda!

Linda: Thanks, Ann. It was so alarming.

Ann: I'm sure it was! So, Paula, what's the alternative to taking drugs?

Paula: Well, Ann, if the hallucinations and delusions are not distressing to the person, and aren't affecting their quality of life, learn how to respond in a way that doesn't cause them to become upset. Don't argue with them about it.

Linda: I know from experience that you don't have to go so far as to claim to see it yourself. Instead, it's just best to reflect back to them what they're saying. For example, you can respond with something like, "You see children playing in the backyard?" or "There's a dog in the house?"

Paula: Yes, if you reflect back what they are saying — instead of immediately denying that what they're saying is true — they aren't as likely to get defensive.

Ann: Is it okay to say that you don't see what they do, or don't hear what they hear, and that you don't know what to make of that fact?

Paula: That's okay to do, especially if they ask you whether you can see it or not!

Ann: Ahh, okay.

Paula: Be puzzled by it, especially if what they're experiencing isn't causing them a lot of distress.

Linda: So, that way, you're saying what you're experiencing without denying what the person with LBD is experiencing. So my previous example of being speechless and in shock was probably a GOOD thing, it bought me some time to process the situation.

Paula: Yes, and the fact that you can't see what they are seeing, sometimes helps the person question to themselves whether what they're perceiving is really there.

Linda: Ooh, Paula! That's a good point.

Paula: Thanks, and here's another technique that might be helpful: If there are guests in your house that you can't see, you can ask them to leave. For example, if your person is seeing children in the back yard or under the table, and it's starting to upset them, you can tell the kids that it's time for them to go home. In this situation you **are** stepping into their reality a little bit.

Ann: You know, when my girlfriend's mother who has LBD was having a hallucination that she was being attacked and it was causing her distress, my girlfriend said, "Hmmm ... this sounds like something that should be investigated! Would you like me to go and investigate this on your behalf?" And her mother said, "Yes!" So, my girlfriend left the room for a bit.

Linda: How did that work out, Ann?

Ann: When my girlfriend returned to her mother's apartment, she told her mother that she'd taken care of the problem. Her mother was very relieved.

Paula: You know, some people with LBD do become aware that they were hallucinating, or realize that what they saw wasn't real, after the fact. If you play along too much and they later realize that for example, there wasn't a cat in the house — the dog would've chased it out — and you had pretended to pet the cat and feed it, well, then they might get angry that you didn't tell them there wasn't a cat!

Linda: Sheesh! Well sometimes you just can't win, right?

Paula: And yet, at the time that cat was very real to them and they wouldn't have accepted your statement that the cat wasn't there! You just have to figure out what responses work best for your particular person.

Linda: Paula, do you have any other suggestions for ways that care partners can respond when their person is experiencing hallucinations?

Paula: Yes, Linda, in fact I just read about an approach that I hadn't encountered before. It was in the July 2023 Lewy Body Dementia Resource Center newsletter. Instead of saying that what the person with LBD sees isn't real, you can say something like, "Sometimes you're able to see things that I can't." It's another non-judgmental way of reacting that can work to keep the situation from becoming stressful.

Ann: It sounds like that may also make them feel special, like they have a super power that others don't have.

Paula: Exactly. And, because people with LBD have lost so much of their prior abilities, it can be nice for them to be told they can do something that others can't.

Ann: Now Paula, so far we've been talking about what it's like to witness a person having a hallucination. But have people living with LBD told you what it's like for them to experience a hallucination?

Paula: Yes, we've talked about this in my support group for persons with LBD and they have a wide variety of experiences with hallucinations.

Linda: Can you share an example or two?

Paula: Most often they report seeing people or children who aren't there, and to some it's very real, very detailed. But to others the figures are shadowy or two-dimensional, even cartoon-like. Some people have even reported hallucinations while they were driving, a person or animal on the road, which led them to stop driving.

Linda: Oooh, that's scary!

Ann: Paula, how readily do they admit having hallucinations? Because, in my experience, they either don't realize it's happening, or they look like they realize something is going on — maybe their eyes are shifting like they're trying to process something or they look baffled or have an empty stare, but they still deny it.

Paula: Yes, that can happen. One possible reason why Robin Williams wasn't diagnosed with LBD before his death, when an autopsy revealed that's what he had, is because he didn't report having hallucinations. His wife and very close friends think that he probably was having them, but was afraid to admit it.

Linda: So some people with LBD think their hallucinations are real and will insist on that. Others realize that the hallucinations aren't real. And in some cases folks are afraid to even admit they're having hallucinations at all.

Paula: Yeah, It's interesting that the people in my support group for persons with LBD do — for the most part — know that they have hallucinations and are willing to describe them. I'm not sure why that is. It may be that hearing other people report their experiences makes it easier for them to accept the possibility that this is happening to them as well.

Linda: Fascinating! So, what do they do when they experience hallucinations?

Paula: Some folks have devised ways to determine if something is really there or if they're hallucinating. For example, if the dog barks at someone, that person is probably there. People have told me that simply waving their arms can disrupt the visual field enough to stop the hallucination.

Ann: That's a helpful tip and worth trying!

Paula: Now, these techniques don't always work. My Dad would sometimes see water on the floor. If I asked him to go try to touch it, the water would go away. Then when he stepped back, the water would reappear! However, this didn't make him doubt the reality of the hallucination. Everything he saw was real to him.

Ann: Didn't you mention to us when we were discussing this episode that Dr. Boeve — and for our listeners who are unfamiliar with him, he's a neurologist with the Rochester Mayo Clinic and specializes in LBD — you said that Dr. Boeve had some suggestions about how to respond to hallucinations?

Paula: Yes, the topic came up in a Facebook support group and I asked Dr. Boeve how to explain hallucinations to someone who is experiencing them. He gave me permission to share his thoughts on Facebook at the time and people found it really helpful.

Linda: What did he say?

Paula: Dr. Boeve said that with LBD the border between being awake and being asleep becomes blurred. And we know that most people with LBD have sleep issues! Hallucinations may be the dream state encroaching on people with LBD while they are still awake.

Ann: So, does it work for a care partner to explain hallucinations as being like waking dreams?

Paula: Yes, this can be much less frightening to a person with LBD than just telling them that they are hallucinating.

Linda: Hmmm, I suppose so. That does sound less frightening. This might be a very useful way to explain hallucinations when friends and relatives ask about what's going on too!

Paula: Yes, Linda! Dr. Boeve also suggested saying that “your mind might be playing tricks on you.” This can work especially well if someone sees an object as something other than what it is, such as mistaking a jacket hanging on a chair as being a person.

Ann: Wow, does that really happen?

Linda: It absolutely does, Ann. I witnessed it quite a few times and I would usually say, “Oh! That's what you see.” You know, after a while, you realize as a care partner that the

hallucinations — in and of themselves — aren't necessarily a problem. Sometimes it's the way that care partners, or family members and friends react and respond to them that makes things difficult.

Paula: The point is that if the hallucinations aren't distressing to the person having them, then the best approach is for the care partners, family members and friends to adapt to the fact that hallucinations happen.

Linda: Right, because they are a very common symptom of LBD.

Ann: It can get to be too much though, it's hard when you are living with someone whose sense of reality is so out of sync with your own! Care partners can even experience symptoms similar to post traumatic stress disorder after the person they've cared for has passed, because they've been coping with an altered reality for so many years.

Linda: Honestly, I can say that it has taken me about five years to process what I experienced with my late husband. And it's one of the reasons I continue to participate in an LBD Support Group. It's so hard to explain what it's like to live with a person who is having hallucinations and delusions to people who haven't experienced it.

Ann: Definitely.

Paula: Caregiver coaching or counseling can help you cope more effectively when dealing with this disconnect.

Linda: Yes, and I suggest when seeking a therapist that you find someone knowledgeable about LBD, or at least about dementia. I found that particularly useful.

Paula: The best way to go about finding a therapist with that specialty is to seek out family assistance organizations or contact your local area agency on aging.

Ann: Another helpful tip is to take a break, even if it's a short one, and give yourself some breathing room. Seek out normal social interactions because spending time and interacting with others in normal — more routine and predictable settings — can help you get your bearings.

Linda: Yes, we talked about this in episode 3, "Is the unpredictability of LBD making you anxious?"

Paula: That's been our most popular episode so far! If you haven't already listened to it, check it out!

Linda: So far today we've talked about what can be done if the hallucinations aren't distressing to the person with LBD. But what if they *are* distressing to the person having them?

Paula: If the person living with LBD becomes upset while experiencing a hallucination, the first thing the care partner should do is acknowledge that distress.

Ann: How would you recommend they approach doing that, Paula?

Paula: The care partner can say something like, “That sounds scary.” Or “That isn’t good.” Or even saying something like “Wow!” or “Oh, no!” can work. Ask how they are feeling. Once you’ve connected with them emotionally, you can then reassure them and distract them.

Ann: Like my girlfriend did when her mom was hallucinating about being attacked. My girlfriend offered to go investigate the issue.

Linda: Yes, their emotions need to be recognized, and after that you can tell them that they’re safe, or that you’ll take care of the situation, if they feel threatened. That way they feel heard *and* understood.

Ann: What if that doesn’t help, Linda? What if they continue to be agitated and upset about hallucinations — or delusions — and their responses are so extreme that it disrupts daily life or becomes dangerous and makes it difficult to provide care?

Linda: Well, Paula what do you think?

Paula: Then it’s time to consider medication. You should keep your medical team up to date about what’s happening even when hallucinations aren’t threatening. But when hallucinations and delusions are causing problems that just can’t be managed by how you respond to them, then it’s time to consider medication.

Ann: Paula, what are some of the drugs that are commonly recommended?

Paula: Drugs like Aricept and Exelon are often prescribed early on to help with cognitive issues. They can also help diminish hallucinations, so if they haven’t already been prescribed, that’s a good first step.

Linda: But they don’t work right away. They can take several weeks to have an effect.

Paula: There are antipsychotic drugs that can have a more immediate effect but you need to be much more cautious about trying them. They do specifically address symptoms like hallucinations, delusions, compulsive behavior, and extreme reactions — what doctors call psychosis. But as mentioned earlier, people can have very different reactions to those drugs!

Linda: Yes, but sometimes the situation calls for using those medications.

Paula: One woman in my support group for persons with LBD gave me permission to use her story as an example of what it is like to have an out of control hallucination.

Ann: What was her experience?

Paula: She was having a persistent hallucination almost every night of a very scary and threatening figure standing by the end of her bed. She tried yelling and screaming at it to go away — but the hallucination persisted. It was extremely frightening to her. She found it impossible to sleep in her own bedroom.

Linda: That sounds awful!

Paula: It was. This kept on for weeks. She told her doctor about it. The first medication they tried wasn't effective for her, even after her doctor adjusted the dosage. Then, her doctor tried Nuplazid, a medication that is approved for people with Parkinson's with dementia who are having psychosis symptoms.

Linda: Well, I've heard of Nuplazid. And I've heard that doctors will sometimes prescribe it off-label for persons with LBD.

Paula: Yes, as you know Linda, LBD is closely related to Parkinson's with Dementia as we explained in our first episode.

Linda: So it wasn't too much of a stretch to prescribe it off label for LBD.

Paula: Right. Her doctor was very experienced with LBD.

Ann: Did that finally help her?

Paula: Yes! She's now experiencing the hallucination much less often and can sleep in her own bedroom again. And when it does happen, it isn't as scary for her.

Ann: So, this is a good example of when using medication to counter hallucinations has worked. And it's important to remember that the first medication a person tries may need to be adjusted or the prescription may need to be changed to something else if a medication isn't working.

Linda: Taking notes is a good way to help monitor how a drug is working. It makes it easier to look back and see how things have changed — or if there's something that's triggering periods of stronger hallucinations or delusional thinking.

Paula: Yes, we can't emphasize enough the importance of taking notes about how things are going. In addition to being useful to you as a care partner, your notes can be invaluable to your medical team.

Linda: So to sum things up, the first approach should be for care partners and people with LBD to learn how to respond to hallucinations.

Paula: Yes, but if the hallucinations are affecting quality of life — causing unpredictable reactions, destructive behavior or long periods of fearfulness or anxiety — that’s when to consider medications.

Linda: And we’ll have information about medications on the Lewy Body Life Resources webpage in the section for this episode.

Ann: Now, we’ve talked about hallucinations, which again involves seeing, hearing, tasting, smelling or feeling things that aren’t there. Let’s delve deeper into delusions, which is when a person *believes* something that isn’t true.

Paula: A delusion can also be a belief that something is going to happen which is really, really unlikely, or that something has happened, when it did not.

Linda: Oh, like accusing the care partner of having an affair!!

Paula: Or when my dad thought he was the governor of North Dakota.

Ann: Or when my grandpa thought my grandmother, who was in her late 80s, was trying to poison him so that she could take all their money and run off with her boyfriend. She used to say to me, “I don’t even know when he thinks I’d have time for a boyfriend because I’m here caring for him 24/7.”

Linda: Yes!

Ann: Could delusions also be thoughts about the need to take some sort of action, you know, actions that aren't appropriate to a situation at all?

Linda: They sure can, Ann. For example, my husband thought he needed to clear everything out of his bedroom closet. I’d find piles of clothing, shoes and other belongings strewn about everywhere in his room. He would be up all night working on this “project.” He was unstoppable while in that state of mind!

Ann: Wow!

Paula: Yes, that’s a perfect example of a delusion in action! He didn’t have any real reason to do that, but something compelled him to do it.

Ann: Hey Linda, you shared a picture with us of your husband’s bedroom after a night like that. Is that something you’d be comfortable with us posting on the LewyBodyLife website?

Linda: Yes, I think that would be okay, Ann, especially since I’ve heard other care partners have experienced this same sort of situation.-

Paula: We could post it on our Resources page.

Linda: That sounds good!

Ann: Okay. Now let's take a step back to something we mentioned earlier and that's accusations, which is a really common and frustrating type of behavior that can result from delusions.

Linda: As we said, these accusations can be about all sorts of things: stealing possessions, taking money, thinking that people are plotting to hurt them. Probably the most difficult accusations for spouses to cope with involve delusions that you are cheating on them, even that you have multiple lovers.

Ann: We'll talk more specifically about that later in this episode.

Paula: The agitation and paranoia that a person with LBD expresses can be due to their own anxiety and bewilderment about what's happening inside them. And that can lead them to make delusional accusations.

Linda: So, how does that work?

Paula: For instance, because they don't understand why they feel so fearful, they convince themselves that something bad must have happened or is about to happen. Or they're confused about why they can't locate something, so they think someone must've taken it from them.

Ann: In other words, Paula, the brain makes up stories about the reason for their mood swings. Dementia isn't just about confused thoughts; it's about confused emotions too!

Paula: Exactly, there has to be a reason why they are so angry! The brain is going to supply an answer of some sort!

Linda: And later on, when they are calm and things make sense again the whole episode may feel like a bad dream or it may be something they don't even remember at all!

Paula: Yes, again, the border between sleep, dreaming, and wakefulness is blurred in folks that have Lewy body dementia. The episode doesn't get stored in long-term memory, just like a dream that you don't remember after you wake up.

Ann: Well, understanding that Paula, what should a care partner do in these situations, when someone is angry and starts making false accusations?

Paula: Reflecting what the person is saying back to them can help with some accusations just as it does with hallucinations. It validates that you are listening and can enable you to acknowledge the feelings behind the accusation.

Linda: I used to respond with questions, for example: “Oh, you think so?” or “That’s what you see, huh?”

Paula: That’s certainly a way of reflecting back to the person. It reminds me of one of the improv techniques that have been taught in caregiver coaching classes, where you repeat what you’ve heard and then continue on with a question.

Linda: It just seemed to me like a non-confrontational way to respond to his delusions.

Ann: Well then Linda, how did your husband respond? Did this approach help de-escalate the situation or did it make it worse?

Linda: Yes it did help, Ann! And When the day came that he finally admitted there was something going on, that he was having problems, and after being appropriately treated with the correct medical “cocktail” — I noticed that sometimes after listening to me, **HE** would respond back with “Oh, you think so?” just like I’d done before to acknowledge his statements that I didn’t necessarily agree with so many times previously.

Ann: That’s interesting, Linda! And also a bit amusing.

Linda: Yeah, it affirmed that what I’d done in the past had resonated with him. I felt validated and that felt good.

Paula: Reflecting back what a person states or asking the sort of questions as you did Linda, can work really well with delusions. It can give the person a chance to just tell their story, whatever they think is going on, without the stress of being contradicted.

Linda: But — you don’t want to do it in a way that validates their accusations! Especially if they are accusing **you** of doing something. Here’s a somewhat amusing example that unfortunately could occur if you do this: if your person says “You had your boyfriend in bed with us last night again.” Well, you *don’t* want to say “Ohh, I had my boyfriend in bed with us last night?”

Ann: No, you don’t want to do that!

Paula: That’s for sure! And as we said earlier, accusations of infidelity are the most difficult to handle. With those sorts of accusations you can try saying something like “I love you, that doesn’t sound like something I would do. I know that would make you feel really bad. I’m sorry.”

Ann: So you aren’t really arguing about it, you’re talking about it from your perspective by saying “that doesn’t sound like something I’d do.”

Linda: And you’re apologizing even though you didn’t do anything wrong. You **are** sorry for how they are feeling because of the delusion.

Paula: You just want to indicate that you are hearing what they are saying, that you aren't dismissing their concern, because that can make them more agitated and defensive.

Ann: Right.

Paula: Now on the other hand, sometimes using a sense of humor is another technique that can work well. For example, saying "There isn't enough room in our bed for that many people!" or "I don't know when I would ever have the time to have an affair — besides, you're the only one who could put up with me!"

Ann: Yes, self-deprecating humor can be very effective in breaking up someone's obsession over those sorts of delusions.

Paula: It's hard for anyone to be angry while they are laughing!

Linda: But it's difficult not to take those types of accusations personally. I know that a lot of care partners have said that being accused of being unfaithful is really painful and hard on them emotionally, especially when they are exhausted from caregiving 24/7!

Paula: Yes, these accusations can feel devastating. It can help to look at it this way: these delusions could be triggered by a fear of being abandoned or by their fear of how much they've lost of themselves. Instead of expressing these fears they angrily lash out at their care partner. It's a tough situation but understanding why they might be doing it can help cultivate that sense of healthy detachment we mentioned in Episode 4.

Linda: Yes, whatever helps you take these delusions in a less personal way.

Ann: Absolutely, and Paula, what are some other common delusions that are difficult to respond to?

Paula: A person living with LBD can start to think that their care partner is an imposter, or a duplicate.

Linda: That type of delusion is called capgras syndrome, right?

Paula: Yes, that's right, Linda. It's spelled C-A-P-G-R-A-S and this type of delusion happens in other types of dementia too. Just like hallucinations it isn't exclusive to LBD, but it does seem to occur earlier in the disease.

Ann: With Capgras, sometimes aren't there multiple versions of the person, not just one imposter? For example a person might think there is a good version, and a mean version, and a version that takes care of them and another version that's their spouse?

Linda: Yes, that does happen, Ann. We sure hear about it during support group meetings.

Ann: So Paula, do neurologists have any idea why these imposter delusions start happening?

Paula: The theory is that it has to do with how the visual processing in the brain is connected to emotional reactions. If the person doesn't have the expected emotional response to seeing someone, their brain interprets this to mean that the person they are looking at isn't really that person.

Ann: That's wild. We know that visual problems are common with LBD. But Capgras adds a whole new level to that!

Paula: Yes, they start asking where the real person is, where their spouse is. They might even demand that their care partner leave the house! Or they try to leave in order to escape from the imposter!

Linda: Wow, so what can be done to cope with that situation, Paula?

Paula: Since it is basically a visual perception issue, it sometimes works if you leave the room, and then before you go back in, you speak out, you introduce yourself. They hear your voice before they see you.

Ann: So, I could say something like, "It's Ann, and I'm here with the ice cream." before I go into the room where my person is?

Paula: Right — and the emotional reaction to your voice should prompt a sense of recognition when they do see you.

Linda: That's incredible! And I'm glad that has worked for people. But are there situations where that doesn't work?

Paula: Yes, it's certainly not a foolproof technique.

Ann: Well, if that doesn't work, what else can they try?

Paula: To answer that question, let me tell a story about dealing with Capgras that I got permission to use from one of the care partners in my support group. His wife was experiencing Capgras and he had tried leaving the room and then announcing himself before he came back in, but that didn't work. What he found did work was to leave the house and go out to his car and call her on the phone.

Ann: So, his wife recognized him as her husband over the phone but not in person?

Paula: Right!

Linda: That had to be so frustrating!

Paula: It really was. She thought there were two Mikes — one Mike who looked like her husband but was just there to help her. And another Mike, who was her husband. She didn't know why her husband never came home and just talked to her on the phone!

Ann: Did it just keep on like that?

Paula: Well, actually it didn't! Mike left town for four days. When he got back from his trip, much to his surprise, his wife recognized him.

Linda: It was like her brain did a reset!

Paula: And she hasn't had any Capgras type delusions since then!

Ann: Wow, that's amazing! And an unexpected happy ending.

Paula: Yes, it is.

Linda: Do you have any other examples of coping with Capgras syndrome?

Paula: Yes, I do. A friend called me on the phone to try to help talk down his wife. She didn't recognize him and thought he was a bad person who'd gotten into their house.

Ann: What happened? What did you do?

Paula: I tried speaking to her but she wasn't being distracted or dissuaded from the delusion by my approach. It was really concerning because the last time they had an episode like this, she ran outside screaming for help and ended up in the hospital.

Ann: Oh my gosh, that's not good. What a horrible situation.

Linda: So, Paula, what did you advise him to do after she wouldn't listen to you?

Paula: I told him to leave the room. He didn't really want to because he was tired and frustrated and just wanted to relax and read a book.

Ann: I can understand why he was feeling so worn down that simply leaving the room felt difficult.

Paula: But I told him that leaving the room was probably the only thing that would calm her down. He ended the conversation, but called back twenty minutes later.

Ann: And were things any better then?

Paula: Yes! He had decided to go downstairs to get the laundry. When he came back upstairs carrying a laundry basket, she recognized him!

Linda: Oh my gosh! So, the laundry basket helped?

Paula: Yes, she was used to seeing him bring up the laundry and that triggered her recognition of him. When he tried to talk about it with her later she didn't remember the incident at all.

Linda: That's really common too, that people don't remember. Or they remember that they were confused but not much more than that. As we've mentioned before, these episodes seem to be like bad dreams where you wake up and your memories about what you were dreaming just sort of fade away.

Ann: I've heard this type of delusion can be about things other than people, for example, thinking that their house isn't really their house.

Paula: Yeah, everything in the house looks the same to them, but they don't think that they're in their real house. It's like an imposter house!

Linda: And sometimes there are many houses, in various places!

Paula: Right Linda. I also know of one person with LBD who, after they had moved, still sometimes saw their old house as if it was coming in and out of view within their new house. They would see stairs where there weren't any or would think they were heading for a room that didn't exist in their new house.

Ann: Ugh, that's tough.

Paula: Yes, people also start asking to go home, even though they are at their home.

Linda: That's sad.

Ann: Yes, it is. How can a care partner respond to that sort of delusion?

Linda: Sometimes in cases where people want to go home, even when they are home, having a conversation about home can help. Bringing up past events, good times, fun things that happened — talking about those memories can make the person feel more secure, more comfortable.

Paula: Wow, maybe the delusion about not being at home is also due to a feeling of disconnection or a lack of emotional response. This must not be my real home because I don't feel like I am at home.

Ann: But talking about what they like about their home can help reconnect them?

Paula: Yes, remember, they aren't looking so much for a physical location but more for that feeling they used to have, of being comfortable, of being at home.

Linda: You know, these imposter delusions are hard to cope with because when they first start happening, they can be really confounding to the care partner as well as the person with LBD.

Ann: Yeah, it's one thing for your person to claim they see a cat or a child that you realize must be a hallucination, but when they claim that you aren't yourself or that their home isn't their home, that's just mind blowing!

Paula: That's true for sure. And we want so much to be able to reach the person and explain to them that they aren't in the situation they think they are in.

Linda: But the problem is when someone with dementia is delusional they're experiencing reality in a way that doesn't let this process happen.

Paula: Yes, Angela Lunde, a Mayo Clinic Dementia Education Specialist we've quoted before, explains it this way: "The person with dementia doesn't have a "boss" in their brain any longer, so they don't respond to our arguments, no matter how logical."

Ann: So, there isn't really any way to talk them out of it?

Paula: Well, sometimes people with LBD realize that what they think they experienced wasn't real and was caused by Lewy. But this usually happens because they see the unreality, not because you were able to point it out.

Linda: So we have to deal with the reality that they're in. And go with flow as they say!

Ann: Wow, well, that's a lot to take in. And speaking of a lot to take in — we're at the end of all that information we wanted to cover today. So, it's time to wrap it up. Thank you for listening.

Paula: We hope you've found this episode helpful.

Ann: And be sure to tune in to our next episode, **Better Safe Than Sorry, Planning for Emergencies**, where we'll talk about what to do when you're faced with an LBD crisis.

Linda: In the meantime, we wish you strength and courage.

Ann: And for more information and a list of the resources specific to today's episode, please visit our website at www.lewybodylife.com.

Paula: And remember, you can get assistance from two great organizations in the US: the Lewy Body Dementia Association helpline at 1-800-539-9767 and from the Lewy Body Dementia Resource Center helpline at 516-218-2026. In the UK, you can contact the Lewy Body Society at 0800 888 6678.

Linda: Thank you, for pointing that out, Paula. And we do have those phone numbers on the Resource page of our website.

Ann: We do. And if you enjoyed this episode, please be sure to check out the other episodes in our series. And if you know someone who may benefit from hearing our discussion today, please forward this podcast on to them! It can be found on the Apple, Spotify and Google podcast platforms.

Music starts

Paula: And finally, we'd like to thank the families in the Minnesota LBD Caregiver Support Group and the Twin Cities Support Group for Persons with LBD for their encouragement and guidance.

Linda: We also really appreciate the financial assistance of this podcast — from various support groups — and from our family members and friends.

Ann: Thanks for joining us and have a great day.

END OF EPISODE 5