## S2, E3: When Outsiders Think You're the Problem: It's Showtime!

**Music starts**

**Lillie Lyon:** 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 Biever and Linda Olsen Engel.

**Music stops**

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

**Paula:** I'm Paula Rice Biever.

**Linda:** And I'm Linda Olsen Engel.

**Ann:** Today we're going to start our episode by asking you, our listeners, a question. Are you seeing your person behave differently when you're home alone versus when others are visiting or you're out in public?

**Paula:** For example, does the person you're supporting act very normal — much like their former self — when you're out and about, but then — when you get back home — they can't continue to function at that level?

**Linda:** Or can they carry on a great conversation with a relative or friend — over the phone, or during a visit — without any signs of confusion or cognitive impairment even though you're seeing a lot of communication and cognitive problems?

**Ann:** Or have you been at a doctor's appointment and your person is able to answer questions and talk conversationally as if nothing is wrong?

**Paula:** If you've experienced situations like these, we're not surprised. In fact, we discuss incidents like these quite a bit in my LBD support group meetings.

There's actually a name for this phenomenon. In the LBD community — it's called Showtime.

**Linda:** And today we're going to discuss what Showtime is, how it can affect your relationships with family and friends, and how it can impact you.

**Paula**: We'll also talk about various strategies you can use to cope with these issues.

**Ann:** But before we delve into today's topic "When Outsiders Think You're the Problem — It's Showtime," we'd like to remind our listeners that we are not professionals and the information we're sharing does not replace seeking the appropriate professional advice for your specific situation.

**Paula:** Yes, Ann, thanks for doing that. We're sharing our experiences and the insights we've gathered from going through this journey. We hope this helps you gain a better understanding of LBD.

**Linda:** And, most importantly, we want you to know you're not alone. Being a Lewy Body care partner can make you feel isolated and it can feel really lonely at times.

**Ann:** Absolutely!

**Linda:** Experiences with my husband and his Showtiming heightened my sense of isolation.

**Ann:** So, Paula, what exactly is Showtime?

**Paula:** Showtime is when a person with LBD steps up in social situations and can interact and carry on conversations like they used to do, but at home they are confused and inconsistent in their ability to converse and to perform tasks that once came easily for them.

**Ann:** And, as I'm sure many of our listeners know from experience, when this first starts to happen, it's really jarring, especially if you don't yet have a diagnosis.

**Linda:** It is! And it's so confusing! You may wonder if maybe your person just isn't trying at home — or at other times when it's just the two of you.

**Ann:** It may even feel like this is something they're doing on purpose, like, they care more about other people and so they put forth greater effort with them.

**Linda:** This is really frustrating!

**Paula:** You may think they are exaggerating their difficulties in order to make you do more work — or to pay more attention to them.

**Linda:** Similar to how a child acts when they want your attention.

**Paula:** But Showtiming isn't something that people with LBD are doing in a manipulative manner. There's something more than conscious intention involved.

**Linda:** It isn't like they're able to flip a switch on and off — it just seems to happen.

**Paula:** Right. Experts and researchers haven't yet been able to identify why people with LBD can temporarily override their symptoms.

**Ann:** But, thankfully, they're aware that this occurs and they're researching it.

**Paula:** You know, early on, when you're not sure what's going on, you might believe that the unusual behaviors you're seeing at home are short-term, just an aberration.

**Linda:** Paula, what do you mean by that?

**Paula:** Well, for example, they may have had an off morning at home. But you take them to the doctor and they do great. And you go to the store and they do great. And it makes you feel like maybe your experience earlier in the day was triggered by something normal, maybe your person hadn't slept well or they were tired or distracted, and that now they're back to their usual self.

**Linda:** Okay, I get it. It's natural to feel that way — especially when your person is in the early stages of LBD and their behavior is still consistent most of the time. Showtime can provide a false sense of security.

**Paula:** Yep, but over time as LBD progresses, you can throw consistency right out the window!

**Ann:** But, at first, when your person's behavior starts to be inconsistent, it's hard to understand what's happening. That's the thing about Showtime; Showtime doesn't last. Lewy symptoms and behaviors come back, usually pretty quickly, once the person with LBD is out of the limelight and feels that it's safe to relax.

**Linda:** Yes, and then the care partner can really pay a cost picking up the pieces in the aftermath of those situations.

**Paula:** The person with LBD is often exhausted by the effort they put out and they just crash.

**Linda:** There's a lot of emotional and mental energy that goes into it. Your person is working really hard to process all that's going on. And then once back in a familiar environment, they just aren't able to hold it together any more.

**Ann:** Making Showtime exhausting for both of you!

**Linda:** So, Paula, what's the difference between Showtime and cognitive fluctuations? I know that having fluctuating symptoms and abilities are considered hallmarks of LBD. Why isn't Showtime considered to be just another fluctuation?

**Paula:** The main difference is that fluctuations happen independent of the environment. Your person can have good days and bad days, good moments and bad moments. For example, a person may not be able to use table utensils at dinner one night, but can use them the following morning at breakfast. Maybe they don't understand a question you are asking or can't verbalize what they want at one point in the day, but a few hours later they have no problem answering questions or explaining themselves. These periods may last several days followed by improvement for a while, and then maybe some other issue comes up.

**Ann:** But those fluctuations don't really correlate to what's happening around them in the way that Showtime does.

**Paula:** Right. Showtime is something that gets triggered by being in a social situation. We all want to put our best foot forward and do our best when we are with other people, but Showtime does more than that.

**Linda:** It actually enables people to overcome their deficits and cognitive confusion, and lets them process — or at least appear to process — what's going on in such a way that they fit in with what is happening.

**Ann:** When the medical community figures out why and how Showtime happens, and why LBD symptoms fluctuate, it'll be a big step forward in understanding how the brain responds to this disease.

**Linda:** And this understanding should eventually lead to better treatment or at least ways to alleviate symptoms.

**Paula:** That would be huge!

**Ann:** So what are the biggest challenges care partners face when their person has Showtime episodes?

**Linda:** For me, I think Showtime made it difficult for other people to understand — or even believe — that something was wrong with my husband. This really made me feel alone and isolated because no one else saw what I was seeing.

**Ann:** So, his Showtiming was that extreme, Linda?

**Linda:** Um-hum. My husband had all the symptoms of LBD — confusion, delusions, hallucinations, inability to complete tasks, and periods of agitation and paranoia. Occasionally, as I mentioned in a previous episode, he even became angry and upset to the point I'd leave the house to help de-escalate the situation and to protect myself.

**Paula:** Yeah, you talked about that in Episode 1 of our second season — "Safety First, How to Protect Yourself if LBD Behavior Becomes Violent."

**Linda:** But he was able to present a really normal demeanor when he was with other people. He'd be calm. He could talk about the things he was interested in. His behaviors would only escalate when he was at home. Early on I didn't know what was happening although I started researching the unusual behaviors I was seeing.

**Paula:** You just knew *something* was going on.

**Linda:** Yes. In 2012, I'd contacted family members to discuss the concerns that I had about changes in my husband's personality. I shared that he was becoming mean, verbally aggressive and accusatory. Everyone kept telling me that he was "just fine."

**Paula:** That's fairly common. People don't believe what they don't see for themselves.

**Linda:** It was hard though, because I was looking both for personal support *and* a way to help him. I was extremely worried about what was happening to my husband.

**Paula:** I've heard similar stories from people in my LBD support group. Friends, relatives, adult children, really anyone who isn't there 24/7, can be taken in by Showtime episodes.

**Ann:** Y'know Linda, I just commend you for making the effort to reach out and to try to have those difficult conversations.

**Linda:** Thank you.

**Ann:** And, when your concerns were dismissed, it must've felt like a punch in the stomach. Like you were being victimized twice. On the home front, you're dealing with someone who is being uncharacteristically mean — in your situation, your husband was being verbally aggressive and accusatory.

**Linda:** He most certainly was.

**Ann:** And then when you attempted to discuss these uncharacteristic changes with others, you were told “He’s just fine.” Whether it’s family, friends or even medical professionals giving that “feedback” — it’s a double whammy.

**Linda:** It felt like I was alone on an island for much of our LBD journey. In fact, my husband’s doctor didn’t give him the Medicare recommended post 65 cognitive screening during his annual wellness checks because he “appeared” so “with it.”

**Ann:** Ugh, that was a missed opportunity!

**Linda:** Yes, and until his final year of life, my husband didn’t allow me to go with him to his annual physicals, so I didn’t even have an opportunity to share my concerns.

**Paula:** I’m sure that was really difficult for you — and so frustrating!

**Linda:** It was! When I finally did accompany him to his annual physical, I gave the doctor a printout of an Alzheimer’s checklist that we had completed together as a couple. This was in 2016.

**Paula:** What convinced him to complete that checklist with you?

**Linda:** I think something happened over Thanksgiving that year that scared him. A few days later he asked me what it was again that I thought he had.

**Ann:** So several years after *you* first had concerns, he finally recognized that something wasn’t right?

**Linda:** Yes, he was willing to complete the check list and even asked me to schedule a doctor’s appointment and accompany him.

**Paula:** So that was a real turning point for you.

**Linda:** It was.

**Ann:** And again, that was roughly *four* years after you’d first approached relatives and friends with your concerns.

**Linda:** Yes, and all through those four years, I didn’t think his dementia was Alzheimer’s but I hadn’t been able to find much information relating specifically to LBD. So I used an Alzheimer’s check list.

**Paula:** The first diagnostic criteria for LBD wasn’t even created until 1996. That’s only 20 years earlier! You were researching LBD symptoms just as information about LBD was becoming available to the public.

**Linda:** Yes, but the answers written on that Alzheimer's checklist clearly demonstrated the emergence of *some form* of dementia.

**Paula:** How did the doctor respond to your list?

**Linda:** The doctor looked at the symptoms on the list and asked me how long they'd been of concern. I said "several years." At that point, the doctor immediately initiated a cognitive screening. When my husband was asked to draw a clock, he got angry and hurled the pen across the room. This was the moment that someone *finally* believed me and started providing help.

**Ann:** I think it's important to acknowledge that HIPPA regulations can make it very difficult to have a discussion with your person's doctor. That said, depending on the practice or clinic, you may be able to call the doctor's office — or drop off a letter or send an email — expressing your concerns.

**Paula:** Good point, Ann. Although the medical staff may not be able to comment back to you about the information you share, they are at least alerted to the fact that they should do a screening. This is something that some of our listeners may not know they can do.

**Ann:** That's right. Although a health provider cannot share personal information with a patient's spouse, adult child or friend unless the patient has given legal permission to do so, the clinic can take the information you've provided into consideration and determine whether an assessment is appropriate.

**Linda:** Yeah, that's really important information and we covered this in detail in our last episode, which was Ready, Set, Go: Planning for Medical Emergencies.

**Paula:** Some health clinics are set up with a portal for a patient's information, and that patient can give permission to someone else to access that portal. They have to initiate it though. It's good to do this when things are going well. Having that access can really be helpful.

**Ann:** But let's get back to our main focus today and that's understanding the concept of Showtime. Paula, what more can you tell us?

**Paula:** Well, you can't really predict when Showtime is going to happen. This means you can't depend on your person being able to do well in any specific social situation.

**Ann:** Sure, sometimes it happens — and sometimes it doesn't.

**Linda:** And when they are Showtiming, you don't know how long they'll be able to keep things together.

**Paula:** I've experienced that first hand with my Dad. We were visiting his brothers and sisters in North Dakota a couple years after he was diagnosed with LBD. We were staying at a large farm house and he was doing pretty well. He had a lot of social contact but we had worked out a good routine. Most of the time, the relatives came to visit him at the farm house so we didn't have to drive him from place to place.

**Ann:** So, it sounds like you structured the visit to help ensure that he had consistency and doing so enabled him to have a pretty good time.

**Paula:** Yes! And his brothers and sisters were really happy to see him. He wasn't having his usual delusions or hallucinations and he could keep up with the chatter. He was pretty much Showtiming all day. Fortunately, these relatives had all visited him in his care residence back home and they understood how LBD was affecting his personality and cognition — although none of them had experienced him having a full meltdown.

**Linda:** Did that happen then?

**Paula:** Yes. Because he was doing so well, on the day before we were leaving we decided to take him to the horse ranch operated by one of his sisters and her family. Beforehand, we went out for breakfast and that went great. But, after some time at the horse ranch, he started getting really anxious about the fact that we were leaving the next day. He got very confused and thought that it was time to go to bed so he could get up for the trip home. He decided he needed to put his pajamas on — and so he started taking his clothes off in front of everyone!

**Ann:** Oh no!

**Paula:** We had to dissuade him from doing that. Showtime was definitely over! We got him into the car and, as we were leaving, he realized what had happened. He felt so badly, that he started yelling apologies out the window!

**Linda:** Poor guy, he had definitely hit the wall, then.

**Paula:** Yeah, when we got back to where we were staying, he went right to bed. What I learned from that incident is to not push things just because everything is going well. Stop before they take a turn for the worse.

**Ann:** Paula, thanks for sharing that story. It's a great example of Showtiming.

**Linda:** And also of how well things can go with a bit of advanced planning.

**Ann:** Yes. So, I'm wondering, is Showtiming unique to LBD?

**Paula:** No, but it's more of an issue because, as I said before, LBD doesn't involve as much in the way of memory loss. People with early stage Alzheimer's

can certainly do okay in some social situations, but they aren't known to be as dramatically different in public than they are at home.

**Ann:** So, do the memory issues that develop with Alzheimer's make it more difficult for a person to Showtime?

**Linda:** Yes, if someone has Alzheimer's it's really common for them to ask the same question over and over, or repeat a story that they just told.

**Ann:** Yeah, and this seems like a good time to remind our listeners that, as we've discussed in previous episodes, LBD doesn't have predictable stages of decline like Alzheimer's.

**Linda:** Right. As people with Alzheimer's move through the stages of the disease, they lose abilities that they don't regain. That's not as likely with LBD. With LBD it is easier to mask the symptoms because what's going on is more of a processing issue. Even if they don't fully understand the conversation, they can carry on as if they do.

**Paula:** So although Showtime-like episodes are not unique to LBD, they're certainly more prevalent.

**Ann:** That's helpful to know.

**Linda:** So let's move on to what can be done to help cope with the issues that Showtime creates for both the person with LBD and their care partner.

**Paula:** It's tough, because Showtime isn't something you want to stop from happening.

**Linda:** That's a good point! The problem with Showtime isn't really Showtime itself, it's what happens because of Showtime, the consequences or maybe the side effects of Showtime.

**Paula:** Like we mentioned earlier, following a Showtime episode it's common for the person with LBD to experience an increased severity of cognitive symptoms — like confusion and delusions, and to have physical symptoms like exhaustion and the inability to interact.

**Linda:** It can really wipe them out for quite a while, sometimes it can take a day or two for them to recover.

**Paula:** So it's important to allow them that recovery time, and not expect them to bounce right back.

**Ann:** Then there are the problems we mentioned earlier that come about for the care partner because the person with LBD does so well in social situations.

**Paula:** People aren't seeing the symptoms that the care partner has told them are happening, so they wonder what's really going on.

**Linda:** And that means the support and understanding that can help the care partner *so much* just isn't happening. The care partner spends a lot of effort trying to describe what kinds of things they're up against.

**Ann:** And they often aren't believed! Which is really why finding a support group of care partners who are experiencing the same thing is so important.

**Linda:** Exactly!

**Ann:** Joining a local or online LBD support group is a good first step. And let's talk about what other things care partners can do.

**Paula:** I think just realizing that Showtime is a thing, and that the symptoms of LBD can fluctuate, can really be helpful.

**Linda:** If you realize that this is part of the disease and expect that your person will have periods when they are doing really well, it might not be so confusing and frustrating when Showtime happens.

**Paula:** After all, it isn't as if you don't want your person to do well and be able to interact and enjoy the situation!

**Linda:** Right!

**Ann:** So what can care partners do when someone says that their person "seems fine?"

**Paula:** First of all, if your person is right there with you, don't start going into detail about all their issues. Give a response that is positive about what is happening right then, like "Things are going well right now." or "We're really happy we can get together with you."

**Ann:** Of course, this depends on the circumstances. If you're having a family meeting to discuss what's happening, that's a different situation.

**Linda:** Yes, but even so, sometimes it's best to talk in private about sensitive issues and challenges rather than in front of your person, even with family members.

**Ann:** Yes, allowing your person as much dignity as possible is important. And providing family members and friends with info about LBD, especially before a family meeting or get together, can help them understand why your person is very high functioning at some times and not at others.

**Paula:** You can explain to people privately or ahead of time that fluctuating symptoms are a hallmark of LBD and that it's common for them to have periods when they are able to do really well. Point out that this isn't Alzheimer's which has a predictable decline but instead there are going to be dramatic swings in their capabilities.

**Linda:** That's why they call it the Lewy Body rollercoaster!

**Paula:** We'll provide a list of resources that can help you better understand and explain Showtime in the Resources section for this episode on our website — LewyBodyLife.com.

**Linda:** Sometimes explaining that many of the problems are associated with sleep and night time behavior can help people accept that there are issues you will experience that they won't.

**Paula:** Because they aren't up at night with your person — they aren't there 24/7!

**Group:** Chuckles in response.

**Ann:** It still can be really difficult for others to accept there's a problem if they haven't seen your person during an off-time.

**Linda:** Yes, with close family it might just be a matter of time — they'll see it eventually. If it's a situation where your person would be safe spending time with them that can help open their eyes. It might need to be an overnight visit or a family vacation.

**Paula:** With distant relatives or with casual friends it might be more difficult.

**Ann:** I've found that it's really difficult for people to understand something they haven't experienced. But once they do experience something similar, especially if it's with someone in their own family, they become much more empathetic.

**Linda:** And with the support from those who do understand — whether it is a support group or friends and family members that have experienced the reality of the symptoms — you can gather the strength needed to keep on keeping on.

**Paula:** This can help you be more patient with other people's lack of understanding.

**Ann:** I think our point is that it's important to have support, someone you can turn to who believes you! Someone you can trust.

**Linda:** Initially, I only had one friend and a couple out-of-town relatives who totally believed me.

**Ann:** That's tough**.**

**Linda:** But I was fortunate that my adult children were on board early.

**Paula:** I've found that some care partners try to protect their adult children from the reality of what the parent with LBD is experiencing and how difficult caregiving can be. They don't want to burden their children until they are forced to reach out for help.

**Ann:** And Showtime episodes can make it easier for adult children to think that things are fine — or that they aren't really *that* bad.

**Linda:** Eventually though, things will get to the point where it can't be glossed over, or the care providing parent can't manage on their own. Then trying to bring the family up to date can become overwhelming.

**Paula:** That's why it is good to get the family involved earlier. Even if there is denial and you don't get the support right away, the conversation is started and it's something you can build on.

**Linda:** If you get a lot of push-back, and have friends or relatives that won't accept what is happening, you may find that those friendships need to be re-evaluated.

**Ann:** Absolutely! The last thing you need when the going gets tough is for others to make it tougher. It's a waste of your time, your energy and your resources.

**LInda:** This might be the time to bring in a social worker or counselor, someone who deals with family situations.

**Paula:** As we've mentioned in our previous episodes, take notes. If you can share specific examples of things that are happening with the social worker, relatives and friends, or even with doctors, that can help.

**Ann:** Or consider recording a video of your person on your phone to capture certain behaviors or symptoms.

**Linda:** Taking a video isn't always easy to do and it can feel pretty invasive, but when it comes to documenting the reality of what's happening, it can be well worth the effort.

**Paula:** Yes, a video can illustrate something you aren't able to describe well, or that you aren't being believed about!

**Linda:** Another technique that can be beneficial is to ask for help. This can make family members aware that you are facing challenges to the point where you need their assistance to get things done.

**Ann:** For example, ask for help with tasks that you or your person used to do, that now you either don't have time to do because of your care partner responsibilities, or that your person can't do because of LBD.

**Linda:** Figure out what would be the most helpful to you, like picking up groceries or taking care of yard work.

**Paula:** Or have a family member or close friend do a task with your person. This can help them see the limitations that your person is experiencing and what sort of assistance they need or are willing to accept.

**Linda:** And that also helps their emotional connection to your person evolve.

**Ann:** It's a hard transition to make when someone who has been independent and capable now has limited abilities and needs care.

**Paula:** That happens in families as parents age normally, but with LBD and other dementias, it's even harder.

**Linda**: It is. So now let's talk about what Showtime is like from the point of view of the person with LBD.

**Paula**: Well, people in my support group who have LBD have talked about Showtime.

**Linda**: And I've also read some very enlightening comments posted on Facebook LBD support group pages.

**Paula**: Yes, I read those same comments. There was one point that people with LBD repeatedly made. It was that they have *always* tried to do their best when they're out in public and that they find it frustrating when they read posts online or hear from their care partner that Showtiming is now causing problems because they seem so normal.

**Linda**: From their point of view, they don't want to be embarrassed in social situations or feel like they don't fit in.

**Ann**: That's understandable, especially if they have a level of self-awareness.

**Paula:** And due to the cognitive losses they are experiencing, they may not realize that maintaining this higher level of ability can cause problems, especially when they are being evaluated by a medical professional to determine a

diagnosis or what treatment might be helpful for a symptom that they are covering up or even denying.

**Linda**: By the way, I'm hearing that the word Showtime isn't regarded as a positive term by some folks with LBD.

**Paula**: Yes, it implies that they are faking it, and putting on a show.

**Linda**: Right. The alternative term that's been suggested is "Surfacing" — like more of their true self is coming up to the surface.

**Paula:** Well, call it Showtime or Surfacing — it's part of the LBD journey.

**Linda**: It sure is!

**Ann:** So here are the key takeaways that we'd like to leave you with when Showtiming — or Surfacing — is happening.

**Paula**: First of all, be in the present moment with them and accept the concept of fluctuations. Take advantage of their increased abilities and enjoy your person.

**Linda**: And be ready for the downside — have a flexible schedule so they have time to recover and don't be alarmed when they are out of it for a while afterwards.

**Ann:** Also, make sure you have the support you need to handle this roller coaster. Educate your family and friends, but don't do it in front of your person unless your person wants to talk about what they're experiencing.

**Paula:** As we wrap up this episode, we want to thank the families in the Minnesota LBD Caregiver Support Group and the Twin Cities Support Group for Persons with LBD for all their encouragement and guidance.

**Linda**: And we also really appreciate the financial assistance of this podcast — from our support group members — and from our family members and friends.

**Ann:** In our next episode, we'll be talking about diagnostic testing. We'll discuss what you can expect during neurology appointments and what the assessment process is.

**Paula:** And we'll talk about new advancements in diagnostic practices that have happened since we started this podcast series.

**Ann:** As you likely know, getting an accurate diagnosis isn't always easy. Some people go through years of neurological testing and a variety of diagnosis before reaching a conclusive result.

**Linda:** And it can be difficult to start the evaluation process, especially if your person isn't ready to accept that something concerning is going on that needs to be evaluated. We'll talk about various ways to manage that situation.

**Ann:** So join us for Season 2, Episode 4: Testing 1, 2, 3: Identifying LBD Isn't Always Easy.

**Linda:** In the meantime, we wish you strength and courage as you travel the LBD journey.

**Paula:** We do. And, if you think the content we covered today may be of benefit to someone else, please share this episode!

**Ann:** Thanks for joining us. For more information and resources about Showtiming, visit our website at lewybodylife.com.

**END EPISODE**