Lewy Body Life

Season 1, Episode 4: Keeping It Cool — Calming Communication Strategies

Music starts

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.

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

Paula: I'm Paula Rice Biever.

Linda: And I'm Linda Olsen Engel. Before we get started with today's topic: Keeping It Cool — Calming Communication Strategies, we'd like to remind our listeners that we are not medical, legal or tax professionals and the information we are sharing here isn't intended to replace seeking appropriate professional advice for your specific situation.

Paula: Yes, Linda, thanks for doing that! We're here to help raise awareness and understanding about LBD and to direct you to other resources you might need.

Ann: And, most importantly, we want you to know you're not alone. Being a Lewy Body care partner can become isolating and feel really lonely at times. So, please know we're here for you.

Linda: Definitely. And we'd really like to thank all the individuals who have listened to our first three episodes and reached out to us via our website contact page at www.LewyBodyLife.com.

Paula: The feedback listeners have shared via email, text messages and phone calls has been much appreciated.

Ann: Speaking of the feedback we received, my girlfriend Terri who is a center director at Cassia — which offers an Adult Day Program — wanted to make sure that our listeners know that Adult Day Programs can be an excellent resource for persons with LBD and their care partners. We briefly mentioned them in Episode 3 but she said they need a bigger shout out as many people don't know Adult Day Programs exist.

Paula: Yes, Ann — Adult Day Programs are important because they can reduce the isolation a person with LBD experiences by getting them out of the house and engaged with others. Plus, Adult Day Programs can provide care partners with a much needed respite.

Linda: It was great that your friend mentioned this to you, Ann.

Ann: Yeah, Linda, it was. As Paula just mentioned, Adult Day Programs are mutually beneficial. The support they provide can help reduce care partner burnout, enabling a care partner to keep their loved one living at home for a longer period.

Paula: Many people in my support groups have had wonderful experiences with Adult Day and other activity programs.

Linda: Right?! If anyone's interested in finding out more about Adult Day Programs, look on the Resource page of our website and check out the Eldercare Locator for US locations. The Locator can be found under "Resources" at www.LewyBodyLife.com. And the Locator also has information about *other* respite programs.

Ann: Now, let's start with today's topic — Keeping It Cool — Calming Communication Strategies. Originally, we'd planned to cover hallucinations and delusions, but we realized we had too much material to cover in one episode.

Paula: As a result, we divided the content we had into three episodes. This episode covers guidelines and hands-on techniques to keep in mind when interacting with the person you are supporting.

Ann: These techniques can keep situations from escalating while helping with more effective communication when Lewy does show up. Knowing there are strategies — and knowing how to use them — can help alleviate some of the anxiety that comes with being an LBD care partner.

Linda: Yes, Ann, it can. And then, in our next episode, Episode 5, we'll talk more specifically about understanding and responding to hallucinations and delusions. And we'll have yet another episode to discuss what to do in emergency situations.

Paula: The approaches and strategies we'll discuss today lay the groundwork for managing tough situations like hallucinations and delusions. They help promote an attitude of healthy detachment when you're interacting with your person.

Linda: And attitude can make a huge difference in how things turn out. I know it sounds trite, but not only can the approach you take make the situation better but it will also help you feel less vulnerable. Looking back, I recall how either my own anxiety or my calmer moods greatly influenced the outcome and the whole tone around situations.

Ann: Interesting, Linda. And I want to go back to a term that Paula just mentioned — healthy detachment. Let’s define that term.

Linda: Great idea, Ann.

Ann: Healthy detachment involves separating yourself emotionally and/or mentally from another person and what they are saying and doing without avoiding or ignoring them. In other words, it means not taking their actions personally.

Paula: You learn not to react right away, but to take a moment to consider the effects of your response.

Linda: Yes, you *try* to, but this can be really hard to do.

Ann: It is, but we’ll talk about how you can learn to do this and why it works!

Paula: While preparing for this episode, we came across a list of caregiver dos and don'ts that we thought would be useful when dealing with challenging situations. Various versions of this list are posted on a lot of dementia caregiving websites.

Linda: Yes, Paula, and after doing some research, we discovered that this list was written back in 1996, by Jo Huey, an Alzheimer’s disease advocate. She came up with "10 Absolutes” for caregivers and it’s still a very popular guideline after all these years!

Ann: We liked it because it seemed relevant for many situations encountered by care partners of persons living with all the various types of dementia, including LBD.

Paula: These guidelines aren’t exclusive to Alzheimer’s.

Linda: But how interesting that Lewy Body Dementia was just beginning to be recognized as a type of dementia at about the same that the list was made back in 1996!

Paula: Yes, it’s a great list and putting these concepts into practice can help put you in a better frame of mind, enabling you to deal with a situation more effectively than you might have otherwise.

Linda: So, why don’t we go through that list and talk about those recommendations?

Paula: Okay! The first three are:

- Agree never argue.
- Divert never reason.
- Distract never shame.

Ann: A girlfriend of mine recently shared a perfect example of what we're talking about here.

Linda: Oooh, tell us what happened, Ann.

Ann: My girlfriend, whose mother has LBD and lives in a care residence, brought a malt over to her mom's for the two of them to share, and she put the leftover portion in the refrigerator. Later, her mother asked her to get the mouse out of the refrigerator. And my girlfriend thought she'd misheard her. She said, "The malt?" "No," her mother replied. "I said, the mouse."

Paula: I'm guessing there wasn't a mouse in the fridge.

Ann: No, there was not. But my girlfriend didn't say a word about it. She just went to the refrigerator and took out the malt for them to share.

Linda: Excellent, so how did her mother respond to that?

Ann: She drank the malt. And when my girlfriend went to leave that day, her mom said, "Thank you for all you do for me. Thank you for getting the mouse — and the malt — out of the refrigerator."

Paula: Yes, that's it exactly. Although your girlfriend didn't openly agree that there was a mouse in the refrigerator, she didn't argue that there wasn't. Your girlfriend diverted her mom by not discussing the mouse and getting the malt out for them to share. And then, your girlfriend distracted her by giving her the malt to drink.

Linda: Wow! She handled that one very well.

Ann: Oh, yes, she did.

Paula: You know, your girlfriend's mother wasn't really upset about the mouse, which enabled your girlfriend to easily divert and distract her. If her mother had been more upset and obsessive about that mouse, this would have been trickier to navigate.

Linda: When someone is really upset, there's some finesse involved in knowing when to divert and distract. Divert and distract may not always be the first things you want to do when someone is having a Lewy moment.

Paula: We'll talk more about this later on.

Ann: For now, let's return to our list of dos and don'ts. A nice thing about this list is that it uses short catchy phrases making it easier to remember the concepts. As Linda mentioned, knowing when and how to put them into practice is a bit more complicated and takes trial and error.

Linda: You're definitely right about that. So, Paula**,** you've shared the first three. What are the next three recommendations on the list?

Paula: The next three are about responding to memory loss issues:

- Reassure, never lecture.
- Reminisce, never say "remember."
- Repeat, never say, "I told you so."

Ann: This seems like a good time to mention that people with LBD typically don't have the same sort of memory issues that people with Alzheimer's do. For example, they may not forget who people are or ask the same questions over and over.

Paula: That's right, Ann. Instead, their short-term memory loss often involves forgetting instructions and how to do tasks — like the steps taken to repair something or for example, how to put out the garbage for pickup.

Linda: I remember incidents like the ones you're talking about. Our trash would get put out, but not in the same place or with the correct orientation. I wouldn't point that out to him; instead I'd sneak out later and fix the situation. I found that sometimes "exit and reset" didn't "feed the monster" and was a *good way to avoid arguments*.

Ann: Another example just recently happened when I was at the gym the other day. I struck up a conversation with a woman in the sauna. We started talking about Pickleball. She shared that her husband — who she imagined would have loved the sport — had died five years ago from LBD. She said that she knew something wasn't right when he was able to remember the names of their friends from long ago, but couldn't remember how to flip a light switch off and on.

Linda: Ann, that really is a great example of what we're talking about here.

Paula: Yes it is. Another example of the types of memory issues that occur with LBD is forgetting an incident, especially one that is emotionally charged, like an argument — and then, when you bring it up again later, the person with LBD adamantly denies that the experience ever happened.

Linda: That's something care partners bring up time and time again.

Paula: Yes, it is a common topic discussed in our support group meetings. It's like the experience doesn't get stored in their long-term memory.

Ann: Interesting, so Paula, how do you suggest care partners handle these types of situations?

Paula: You know, the guideline says “repeat, never say I told you so.” It really doesn’t serve any purpose to say “I told you about that” or “Why didn’t you get ready like I asked you to?” You just need to figure out what the next thing that needs to happen is, and work on that.

Ann: It sounds like you’re saying to take one step at a time. Don’t give multi-step instructions.

Paula: Yes, that really helps!

Linda: This is all part of practicing healthy detachment. It’s hard not to feel defensive though, when someone claims we didn’t ask or tell them about something, and *we know very well we did.* But it doesn’t improve the situation to remind them that we already told them something. They, in turn, just become *more* defensive.

Paula: Yes, but feeling misunderstood or unheard can be so frustrating for a care partner. It’s natural to want acknowledgement for our efforts — whether we’re getting something done or preparing for an event. But when someone has LBD that isn’t something you can expect to happen the way it used to.

Ann: And it takes time to reframe your expectations of what the person with LBD is now capable of.

Paula: You know, getting back to our discussion about memory loss, it’s important to realize that sometimes people have a combination of dementia types that influence what type of memory and behavior issues they have.

Linda: So true! A post mortem brain autopsy confirmed the presence of *both* Lewy bodies and Alzheimer’s in my late husband’s disease profile.

Ann: Yes, people can have a mixture of symptoms as a result. They might have more memory issues if Alzheimer’s is present along with LBD.

Paula: Yes, they may.

Linda: Alright, well let’s keep going. What are the rest of the guidelines, Paula?

Paula: The last four guidelines are:

- Say, “Do what you can do,” never say “You can’t.”
- Ask, never demand.
- Encourage, never condescend.
- Reinforce, never force.

Linda: Thanks! Most of these seem self explanatory, except (for me) the last one. Can you explain what is meant by “*Re*inforce, never force?”

Paula: Sure. This means don't use a commanding tone of voice to tell somebody what to do. Instead, try inviting someone to do something, or maybe ask what their choice is about some aspect of a task that needs to get done. Regard yourself as a support for their efforts, as reinforcement, not an enforcer.

Linda: What an interesting approach!

Ann: So the goal is to give the person a sense of buy-in and independence. To help that person feel like they have a choice in the matter.

Linda: Makes perfect sense – plus, you're treating them in a respectful manner and I like that.

Paula: That's right, Linda! Watching someone you have been close to for years lose their abilities isn't easy for care partners.

Linda: And It's also extremely difficult for the person with LBD to accept.

Paula: So, if a care partner starts barking out commands to get things done, there's a good chance the person with LBD is going to rebel and refuse to do what they've been asked to do. Because it's often the only thing they feel they have the power to do.

Linda: Yes, very likely so — and once someone says "no" you have *that* issue to work around. Then the only solution may be to take a break and come back later with a different approach.

Ann: What's an example of a different approach? What do you do when someone refuses to take a shower, or eat a meal or take their medications?

Linda: I know that explaining why they need to shower or eat when they don't want to doesn't usually inspire them to do those things!

Paula: (laugh) That's true! As we said previously, sometimes giving them some buy-in, an option of some sort they can choose, can work well, like asking if they want to try out the new bath towels to see if they are any good.

Ann: So instead of saying "You need to take your medications," say "Can I get you a glass of water for you to take with your pills?"

Paula: Or ask if they want to do something now or a little later.

Linda: Sounds like good approaches to try in those situations.

Ann: All the suggestions on this list are pointing out how care partners can approach the various situations and difficult interactions that can happen with LBD in a different way. Doing this may feel very counterintuitive at first and, as you mentioned earlier Paula, it takes practice.

Paula: It sure does, Ann.

Linda: Here’s a thought: Let's put this list on our website page in case some listeners aren’t able to take notes right now — or they are taking notes but want to make sure they didn’t miss anything.

Ann: Great idea, Linda! And it might be helpful for care partners to share this list with family members and friends who may be helping out with the caregiving or coming over to visit.

Linda: Yes, and sharing these ideas ahead of a visit or family event encourages the people around you to feel more involved.

Paula: Absolutely. And that way family members and friends might better understand what you’re doing when they see you put these concepts into practice. This will enable them to learn from your example how to respond more effectively themselves, lessening the chances of agitation and upset.

Ann: At the very least, care partners and family members might remember these suggestions in the aftermath of a situation and then be able to plan ahead and react differently in the future.

Linda: Mmm**,** I also remember observing my husband while he was in the presence of visitors, and his reactions to certain styles of communication could leave him agitated for days. This was certainly not the visitors’ intention. Their intent was to be helpful.

Ann: You learned from experience in those situations what worked and what didn’t.

Linda: Yes, I could see that some of the ways visitors approached him only made him more nervous.

Paula: Just being aware that there are different ways to approach someone or to react opens up opportunities for you to experiment and discover which type of responses are more effective.

Ann: You can then share what works best for your person with others.

Linda: You’ve sparked another helpful idea here! Creating a “practice script” in your mind for future interactions can be a beneficial “hands-on” approach for care partners. I know it certainly helped me.

Paula: It does help to think ahead about how to respond to various situations that you know from experience might come up again.

Ann: And then there’s the fact that no matter how hard some people try, for reasons that we may not ever understand, their simple presence — even when they are employing strategies that typically work, may agitate your person.

Linda: In those situations, you need to be an advocate for your person. So, instead of having that well-intended friend or family member interact with, or care for the person who has Lewy, you can rely on those people in other ways.

Ann: Exactly. Those individuals can still be a part of your care team but provide indirect support. For example, you can meet them for lunch or to go on a walk or ask them to run an errand for you when you can’t step out.

Linda: Great ideas for handling that type of situation, Ann!

Paula: Remember that the main purpose of these strategies is to communicate more effectively and to keep things from escalating when someone becomes upset.

Ann: But when you first start using these methods, you may feel awkward — like you are appeasing or giving in to the person. Or even like you’re being manipulative.

Linda: Spot on, Ann! And at first, incorporating these new techniques isn’t always comfortable. Prior to obtaining a Lewy Body diagnosis, it’s natural to “argue” and “explain” when interacting with someone. But as mentioned in a previous podcast episode, that approach doesn’t work anymore!

Paula: So true. When you keep in mind that the goal is to get your message heard, get a task accomplished or to help prevent situations from escalating, that can motivate you to work through your personal discomfort.

Linda: Your reaction to what the person with LBD says and does in turn affects their outlook and response.

Ann: Being mindful of this can be so useful. Paula, what other techniques work well?

Paula: Another good technique is called validation. This is a way to acknowledge the thoughts and emotions of the person you are interacting with.

Linda: You’re so good with examples, do you have one here?

Paula: Here’s a simple example: If someone starts acting agitated, you can say something that shows you understand that they are upset or having a response to what is happening, like, “You look anxious.” Or “You look scared.”

Ann: Or “I see you don’t like that.” Or “You’re upset about that.”

LInda: Now *that* reminds me how my husband always got upset when the phone would ring. He’d act startled and even make faces. I didn’t use validation then, and looking back, I sure wish I had!

Paula: Not only does this technique acknowledge how the person is feeling but it buys you some time to figure out how you want to respond.

Ann: It sure does. Validation works for a lot of reasons.

Linda: So true! And as previously mentioned, when someone with Lewy Body dementia is agitated, telling them to calm down will likely only agitate them more.

Ann: For sure. Really, I think most of us feel that way! Acknowledging that the person is agitated can be much more effective.

Paula: Yes, it can. No one likes to be told to calm down!

Ann: Remember when we discussed the first three tips and mentioned that sometimes diverting and distracting isn’t always the first thing to try when someone is having a difficult time?

Linda: Yes, we said that if someone is really upset that might not work.

Paula: Using validation, reflecting back what they are feeling and thinking, that can help calm things down.

Ann: Then diverting and distracting is more likely to bring the situation to a close.

Linda: Again, I wish I had known more about that approach when I was having difficult interactions with my husband!

Paula: Teepa Snow, a dementia educator, likes to use phrases like “That isn’t good” or “That doesn’t sound right.” She also suggests saying “I’m sorry, this is hard!” She encourages care partners to use these phrases as a way to join in to their person’s reality.

Linda: Paula, I’m glad you mentioned Teepa Snow as a resource. She has some great video clips demonstrating how to interact using validation. She has had such an impact in the field of dementia with her positive approach to care!

Ann: The responses that Teepa suggests go a step beyond reflecting back what the person with LBD is experiencing. Saying those sorts of things shows empathy as well, it shows that you understand.

Paula: When you think about it, all these techniques we have talked about can be useful not just for interacting with people who have dementia — they can also work in many situations with just about anyone.

Ann: Yes, these are good communication techniques in general.

Linda: And learning to communicate involves a lot more than just words!

Paula: Angela Lunde, a dementia educator at the Mayo Clinic, says, “We can learn to communicate with our words, tone and body language in ways that can generate reassurance and a sense of contentment.” By communicating in this way, Angela points out we’re letting go of our own need to control something that we just cannot fix.

Ann: And, again, as we mentioned earlier, that’s not an easy thing to do.

Linda: Yes, and remember that if their behavior isn’t harmful, we can acknowledge their feelings and enter into their reality and just accept it. This makes us an ally rather than an enemy.

Paula: Entering their reality can also be an effective way to approach hallucinations and delusions as well, which we’re going to discuss in our next episode.

Ann: So tune in to our next episode, “Hallucinations and Delusions? Go with the Flow.“

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

Paula: Remember that 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: And we do have those phone numbers on our website, right?

Ann: We do. And for more information and a list of the resources discussed in today’s episode, please visit our website at www.lewybodylife.com.

Linda: So, if you enjoyed this episode, please be sure to check out the other episodes in our series.

Ann: 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 or Google podcast platforms.

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 series — from various support groups — and from our family members and friends.

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

Ann: Thanks for joining us today!

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