

## **Lewy Body Life**

### **Season 2, Episode 1: Safety First — How to Protect Yourself if LBD Behavior Becomes Violent**

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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 glad you've joined us for today's episode: Safety First — How to Protect Yourself If LBD Behavior Becomes Violent. In this episode, we'll discuss the types of behavioral changes that can occur with people who have LBD and — an often overlooked topic — how to protect yourself if the person with LBD becomes emotionally abusive, physically aggressive or even violent.

**Linda:** Before we delve into today's topic, we'd just like to remind our listeners that we're sharing our personal experiences and the information here is not intended to replace seeking the appropriate medical, legal or tax advice for your specific situation.

**Ann:** Yes, thanks for that reminder Linda.

**Paula:** Sometimes, especially early in the disease, it's hard to imagine that your person — who may have been good natured, kind and thoughtful, even a very gentle soul — may put you in danger.

**Linda:** These are things that I never thought I'd be dealing with when my husband and I started our LBD journey. But eventually I had to.

**Paula:** Linda, many of my LBD support group care partners also express how surprised they are when their LBD person experiences drastic personality changes and threatens their personal safety. This doesn't happen in every case, LBD affects people very differently.

**Ann:** Mmm, yes. However, being aware of this possibility and knowing what to do if that does occur can lead to better outcomes for all involved.

**Linda:** Yes, again, I can't stress enough how I never thought my husband would become violent. I never thought that would happen. Initially, he just had short unpredictable bursts of anger, hostility and agitation.

**Paula:** And Linda, in Season 1, Episode 4, we talked about various ways to handle agitation and how sometimes calmly leaving the room can work well.

**Linda:** Yes it does. I used the exit and reset approach several times to de-escalate situations. I'd simply leave the room and go elsewhere in the house. Or sometimes it worked to drive away and return home after a few minutes.

**Ann:** But sometimes you need to do more than that to protect yourself because things can shift from bad to worse in a split second.

**Paula:** So, if your person with LBD is becoming more prone to angry outbursts, is having unpredictable reactions, or is acting out paranoid type delusions that they are in danger, don't take this lightly. Like Ann said, things can escalate in a hurry!

**Linda:** Absolutely, Paula. That's why creating a personal safety plan is so important.

**Ann:** Yes, it is. So let's go deeper on this topic. Linda, are you comfortable sharing some of the things that you experienced as the situation with your husband — who had LBD — began to escalate?

**Linda:** Yes, with a couple important reminders. As just mentioned, I did not expect my husband to ever become physically violent. Also, looking back, he had refused to see a doctor and was self medicating with alcohol instead. An earlier diagnosis and the appropriate prescriptions may have really helped our journey.

**Paula:** It's not uncommon for a person with LBD to refuse to go to the doctor or to self medicate. And even when alcohol isn't involved, violent and threatening behavior can and does occur.

**Ann:** Okay, so Linda what sort of situations came up for you that made you more concerned for your safety and how did you respond to them?

**Linda:** As the disease progressed, I started confiding in others that I was becoming fearful about his actions towards me.

**Paula:** What was making you fearful, Linda?

**Linda:** He'd just start getting angry for no apparent reason, which was the first big personality change. Eventually his anger escalated and I knew it was time for me to grab my keys and leave the house. I could sense danger in the tone of his voice, his hyperactivity, and he had a manic look in his eyes.

**Ann:** Well, I'm sure some of our listeners have seen those same behavioral shifts and felt that same sense of danger.-

**Paula:** Yes, members in my support group have also described these dramatic changes in personality happening. This can be really surprising and unexpected. It can catch you off guard and you don't know how to react.

**Ann:** That's why it's very helpful for care partners to know that this can happen. Now, getting back to Linda's story, Linda after you left home what happened when you returned?

**Linda:** Sometimes he would have put himself to bed — and we would've avoided a confrontational crisis. Other times he'd simply forget that anything had happened at all.

**Ann:** So, Linda, there you were in a situation that was unpredictable and volatile and, understandably, you were feeling threatened. How did you handle that? I mean, what steps did you take to protect yourself?

**Linda:** Well, we were sleeping in separate bedrooms by then, because he'd been acting out his dreams and sometimes attacking me. So, I started sleeping in a room with a locked door.

**Paula:** Sleeping in separate rooms is often the first step in protecting yourself because of the harm that can occur when the person with LBD is acting out their dreams — the REM Sleep Behavior Disorder that is common with LBD.

**Ann:** And locking the door at night for some added peace of mind is a great idea.

**Paula:** If your door doesn't already have a lock on it, it's easy enough to add one.

**Ann:** Linda, what other safety precautions did you take?

**Linda:** Mmmm, I thought about what items in our home could be used as weapons. I removed our sharp knives from the kitchen counter and I found a gun he'd stashed under the bed. I removed it from the house and placed it in locked storage.

**Paula:** It is really important to take a critical look at your home environment with personal safety in mind.

**Ann:** So, Linda, you'd removed or hidden items that could be used as weapons. What else did you do?

**Linda:** You know, Ann, I realized that I needed to be prepared to leave the house quickly and even perhaps stay away overnight. So I packed an emergency bag, put it in my car, and kept the gas tank at least half full. Some of the friends that I'd confided in offered me safe haven in their homes — so I knew that if I needed to leave for a longer period of time, I had places to go.

**Ann:** Wow, well thanks for sharing all of that. These are all really good practical things that people can do to protect themselves if their person with LBD becomes threatening or violent. And they illustrate why it's important to have an emergency plan.

**Paula:** Linda, I'm curious, what sort of items did you include in your emergency bag?

**Linda:** Mine contained a variety of clothing, some pajamas, Band-Aids, medications, a toothbrush, toothpaste, a phone charger, and water... but then we always have water in the car.

**Ann:** When you live in an urban area you typically have 24-hour access to a drug store, a grocery store or other types of conveniences. If you're in a more rural area, you don't.

**Paula:** So, pack accordingly — pretty much the essentials that you'd need if you had to stay away from your home for a while.

**Linda:** Yes, and again I want to emphasize that at first all these preparations seemed extreme. However, the day came when I needed to escape to protect myself, and was I ever glad that I'd prepared!

**Ann:** If you're a person who is hesitating or questioning whether an emergency plan is really necessary, the answer is, you never know. So, it's better to have a plan and not need it, than to need a plan and not have one.

**Linda:** Umm, hmmm!

**Paula:** Many people are surprised when they do need to implement their emergency plan. And Linda, like you, care partners in my support group have shared how they've lined up a safe place to go.

**Linda:** Really? It IS nice when family members and friends are willing to take you in at a moment's notice, like in my case.

**Ann:** But if someone doesn't have that option, what can they do?

**Paula:** Well, it's a good idea to have a list of nearby places — like hotels or motels — that you can go to. The list should include their names, addresses and phone numbers.

**Ann:** Yeah, you can add this information into your phone contacts or keep the list in your emergency bag. That way, even when you're feeling rattled, you can easily go to your list and call or search online to find a room from the safety of your vehicle or another location — instead of driving around looking for a place — or trying to figure out where to go at the last minute.

**Linda:** Excellent idea, Ann! I remember a time when we were at our cabin and I didn't have all the options I had at home. A list like that would have been so helpful, instead of driving around randomly for hours.

**Paula:** Even if you just need a place to sit, think, and re-evaluate - perhaps a coffee shop, a shopping mall, or a restaurant that stays open late - having that place in mind as an option can be really helpful when you are upset.

**Ann:** So, we've talked about storing or removing anything from your home that can be used as a weapon, having an emergency bag in the car, keeping your car ready to go, and having friends that'll take you in or a list of places you can go. Paula and Linda, are there other things people should keep in mind to prepare for a crisis?

**Paula:** While we were preparing for this episode, Linda and I participated in an emergency planning webinar and one recommendation we really liked was to back your car into the garage so that the car was parked facing out for a quick exit.

**Linda:** I hadn't personally thought of that back then, but it makes perfect sense.

**Paula:** You'll also want to have cash or a credit card with you to cover any expenses.

**Linda:** For sure, Paula! Yeah.

**Ann:** But Linda, did you feel it was safe to leave your husband alone when you left your home — or cabin?

**Linda:** Good question. Yes, or I wouldn't have left him — I would have called 911. I was always prepared to call for emergency help if either of us needed that level of intervention.

**Ann:** So, then what should a care partner do after they leave a dangerous situation? How do they know when — or even if — it's safe to go back home?

**Linda:** Oh, each situation varies. Sometimes a phone call to your person can help you gauge their mood. Or you could drive by and see if things look OK.

**Paula:** You need to be really careful re-entering a situation. Usually, with time, the mood will have passed and the person with LBD will be exhausted. But if not, you may need to make a second quick exit.

**Linda:** Another idea is to have a camera installed at home. That'll enable you to remotely monitor what's happening and can help you determine when it IS safe to return.

**Ann:** You may even want to have someone come back to your home with you — which brings up my next question: At what point does it make sense to get the police involved?

**Paula:** The sooner the better, Ann. If your person is having delusions and behaviors that are concerning and they're starting to act aggressively to the point where you feel threatened, it's a really good idea to proactively contact the police.

**Linda:** Yes, and make sure to mention you're a care partner and that the person you're caring for has dementia and is a vulnerable adult. Also, think about how you'll explain the situation to the first-responders when they arrive at your house.

**Ann:** For sure, you want the police to know that this is a person with a disease — not a criminal. And Paula, getting back to what you just said, what's the benefit of contacting the police if you aren't in a crisis?

**Paula:** Many police departments have mental health or special needs awareness programs. If your police department does, they can enter key information about your situation into their database. That way they can bring up the information if they get a call or 911 dispatch at a later date.

**Linda:** I really like that idea. I wish I had known to do that.

**Paula:** Another thing to consider — if you can't leave your home — is where you can go inside your home to safely call for help.

**Linda:** As we mentioned before, a room with a locked door might offer protection until help arrives. If that's not an option, move a piece of heavy furniture in front of the door or keep a doorstop in the room.

**Ann:** You may even want to keep a few emergency supplies in that room too.

**Linda:** Ah, like a burner phone in case you don't have time to grab your usual one.

**Paula:** You'll want to make sure to keep your emergency phone charged, of course!

**Ann:** Yes you will and having a room to go to is a good fallback option. But you've got to keep in mind that your personal safety is of utmost importance. We can't emphasize

that enough. If you're being threatened or are in danger, it's best to leave your home and then call for help. Always err on the side of caution and self-preservation.

**Linda:** Once a threatening incident has happened, you need to become proactive — you have to seek outside options for help.

**Paula:** Yes, don't hesitate. Take steps to help ensure you're not in this type of situation again, and that your person gets the help they need.

**Ann:** And let's be honest, sometimes that's easier said than done. Paula, what are some of the steps you recommend?

**Paula:** Contact family assistance organizations — like Lutheran Social Services or Jewish Family Services — that can help you assess the situation and determine what the appropriate next steps are. They provide caregiver counseling without regard to your religious affiliation. Your local Area Agency on Aging can also provide information about organizations in your region.

**Linda:** This is about the time that I called the Lewy Body Dementia Association Helpline, to seek help in our journey. I left a message and Paula, you actually returned my call later, and that was a turning point for me. I learned about the caregiver support groups and other local resources that you shared.

**Paula:** The LBD Association is a great resource because they can help you find the assistance that you need before, during or after a crisis.

**Ann:** Linda, do you have a phone number for the Lewy Body Dementia Association so we can share that with our listeners?

**Linda:** I sure do! The number is 1-800-539-9767. Be aware that you may need to leave a message — and someone will call you back.

**Paula:** Another great resource is the Alzheimer's Association Hotline. It's answered 24/7. And they deal with all types of dementia, not just Alzheimer's. Their number is 1-800-272-3900. And both of these phone numbers are listed on our website.

**Ann:** Yeah, they are. Paula, you've mentioned that if a care partner is panicking and doesn't know how to deal with a delusional episode — or is involved in a situation they don't know how to handle — the Alzheimer's Association Hotline can help coach them through it.

**Paula:** Yes, one of the people I spoke to as a Lewy Buddy told me how they had called the Alzheimer's Association in the midst of a crisis where their person was attempting to leave the house, thinking their caregiver was an imposter and a bad person. They were coached successfully through that situation.

**Linda:** Wow! That was great! But again, if your safety is threatened you may just need to leave and call once you are in a safe place.

**Paula:** That's right Linda. The Alzheimer's Association can also put you in touch with local resources to assist you.

**Ann:** In addition we have a link to an excellent article by Timothy Hudson on our website's Resource page that can help people prepare for these types of emergencies. It's an in-depth article called "Stay safe with Lewy Body Dementia psychotic dangers."

**Linda:** I've read the article and I highly recommend it.

**Ann:** Like we just mentioned, once a crisis like this has happened, it's a game changer. Paula, what sort of circumstances do people find themselves in?

**Paula:** Well, your person may need to be hospitalized in a geriatric psych ward, to be stabilized. This enables medications to be adjusted in a safe environment.

**Linda:** Wow, when this first happened to my husband, it was shocking and alarming to me and our adult children that he actually needed psych ward placement.

**Ann:** I can only imagine! And Linda was this before you realized that the purpose of his stay was to stabilize him and adjust his medications?

**Linda:** Yes, it was, Ann, and it wasn't until after his third admission — when they figured out an effective combination of medications — that we saw positive changes in his behavior.

**Ann:** I'm going to reiterate what you just said, Linda. And that was that he was admitted three times before they stabilized him. But, the good news was that he was in a secure and safe environment and you were safe at home.

**Linda:** Mm hmm. That's right, Ann.

**Paula:** Yeah, it can take a while to get medications figured out — and for your person to adapt to the new meds. Everyone reacts uniquely to the various drugs. Those reactions can be closely monitored during a hospital stay to determine what works well and what should be avoided.

**Linda:** Sometimes it takes a crisis and a hospital stay to get medical professionals involved, especially if your person has been refusing assessment and your family and friends haven't recognized the sorts of issues that you've been living with.

**Ann:** Yes, people with LBD often appear to be very high functioning when interacting with others at social events or even at appointments — this is called "showtiming."



We'll cover more about this in a future episode "When Outsiders Think You're the Problem: It's Showtime."

**Linda:** Be sure to watch for that upcoming episode.

**Paula:** Now, getting back to once your person is stabilized, then you're faced with another decision: What's the best care environment for your person?

**Linda:** So, Paula, you mean like whether they can return back home or if they need more care than you can provide?

**Paula:** Yes, and there's a range of options. Sometimes adding in more home care and day activity programs is sufficient. Some folks do stabilize after the correct medications and a more appropriate and consistent environment is implemented at home.

**Linda:** But in many cases, more intensive care is needed, such as nursing homes with special behavioral units, or assisted living secured memory care or adult foster care homes with a high staff to resident ratio.

**Paula:** A hospital social worker or a family assistance organization can help you determine whether it's safe for them to return home and can help you locate the appropriate care residence.

**Linda:** The hospital social worker is a good place to start, but remember that their goal is to get your person discharged. Family organizations and each individual's state's Ombudsman for Long Term Care can help you evaluate what is available in your area.

**Paula:** As I mentioned before, we have information about those organizations on our website.

**Ann:** Now, Linda, as I recall, in your situation you were told that your husband could not return home.

**Linda:** Yes, Ann, the hospital team surrounded me and told me that I had to pursue other options because it was no longer safe for either of us to keep him at home.

**Ann:** Was this a surprise to you?

**Linda:** I had already been concerned about his safety because he was falling, so I'd made visits to possible care facilities. So, I was somewhat prepared and then was able to make recommendations to the team that helped determine the best location for him.

**Paula:** Linda, it's fortunate that you'd already started the search for alternative care. And it's always best if you can take a tour and talk with the care director before making any decisions.

**Linda:** It sure is, Paula. Taking tours beforehand gave me a better idea about how my husband would interact with staff, what the other residents were like, and whether the place was, overall, a good fit for him.

**Ann:** When you're visiting these residences, make sure to ask about how they handle behavioral issues and what their procedure is for dealing with emergencies.

**Linda:** Absolutely, and also remember, you don't stop being a caregiver once your person is in a care residence. You're still the main person to advocate for their wellbeing. You also need to advocate for your own well-being during this process, and taking care of yourself will make you a better care partner!

**Paula:** Yes, you need to recognize when you're no longer able to care for your person at home, that their needs are too much for you to manage.

**Ann:** And if the best option is for your person is to return home, make sure you prepare yourself for what's ahead. Bring in home care, take caregiver coaching and counseling classes, and make sure you have a support network of people who understand your circumstances.

**Linda:** Yes! Know what your options are if another crisis occurs.

**Paula:** We talked earlier about making a safety plan in order to be prepared for a crisis. When we were looking for resources for this episode, several organizations we contacted suggested using a Domestic Violence Personalized Safety Plan as a template — so we've included one on our website in the resources section for this episode.

**Linda:** Ooh, that's good; you can review the steps in this plan and then alter it to your own situation. You can also seek out counseling to help you navigate this journey, and to look out for your own emotional and physical wellbeing.

**Ann:** Yes, great ideas Linda. Dealing with the possibility of violent behavior is a really difficult part of being an LBD care partner. We encourage you to reach out for guidance and help.

**Paula:** We've covered a lot for you to consider, and this seems like a good time to wrap up this episode.

**Ann:** I agree, Paula. And remember there are a lot of things that you can't plan for with LBD. So plan for what you can. Now, before we go, let's talk about our next episode.

**Paula:** Yes, in our next episode, "Ready, Set, Go: Planning for Medical Emergencies," we'll discuss how to prepare for and react to a medical emergency involving you or your LBD person. |

**Linda:** Another thing, 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 all their encouragement and guidance.

**Paula:** We also really appreciate the financial assistance of this podcast — from our support group members — and from our family members and friends.”

**Ann:** Yes, we do. And for more information about today's topic, check out the resources on our website at [LewyBodyLife.Com](http://LewyBodyLife.Com). And, in the meantime, stay safe and thanks for listening!

**END EPISODE**