

Lewy Body Life

Season 1, Episode 1: Lewy Body 101: The Roller Coaster Ride

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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 everybody! I'm Ann Brucciani Lyon.

Paula: I'm Paula Rice Bieber.

Linda: and I'm Linda Olsen Engel.

Paula: Before we get started with today's topic, "Lewy Body 101: The Roller Coaster Ride," we'd like to thank the families in the Minnesota LBD Caregiver Support Group and the Twin Cities Support Group for Persons with Lewy Body Dementia.

Linda: Definitely. We appreciate all input, encouragement and financial assistance of this podcast series - from the support groups and from our family members and friends who have listened to our episodes and helped craft them into what they are now.

Ann: Our listeners should also know that we are not medical, legal or tax professionals and the information shared here is not intended to replace seeking the appropriate professional advice for your specific situation.

Paula: We're here to help raise awareness and understanding and hope that the information we share will help guide you, our listeners, to the resources you need.

Linda: And, most importantly, we want you to know you're not alone. Being a Lewy Body caregiver can become isolating and feel really lonely at times.

Paula: So we want you to know that we are here for you.

Linda: That's right.

Ann: Since this is our first episode, we'd like to take a moment to introduce ourselves. I'm Ann Brucciani Lyon. I met Paula and Linda while attending a Lewy Body Dementia support group.

I have extended family members and family friends who have been diagnosed with — or were suspected of having — Lewy Body Dementia. I say suspected because they displayed symptoms of the disease before 1995 when there was an official term for it.

I immediately felt a deep connection with Paula and Linda when we met. These two women have demonstrated incredible strength navigating this disease and are extremely knowledgeable about what the LBD journey is like.

Ann: Paula, why don't you take a moment to share your history with LBD?

Paula: Sounds good. I am Paula Rice Biever.

My dad was diagnosed with LBD in 2008. After he was diagnosed, my husband Erik and I joined the Minnesota LBD Caregiver Support Group, which proved to be an invaluable resource for us.

Later on Erik and I became the co-facilitators of this group in 2011 after my Dad passed away. We wanted to make sure other people could get the same support that was so helpful to us.

Ann: Speaking of which, you don't have just one support group that you lead, you have two. Can you tell us about the second one?

Paula: Yes, that's the Twin Cities Support Group for Persons with Lewy Body Dementia.

Linda: Paula, when did you start that group?

Paula: I started that group in 2017 to provide support for individuals with LBD and their care partners. It's the type of group that I wished my father and I could have participated in together after he was diagnosed.

Ann: As if that wasn't a big enough commitment to LBD, you're also a volunteer with the Lewy Body Dementia Association.

Paula: Yes, I am. I'm what they call a "Lewy Buddy."

Ann: For our listeners who don't know what that is, a Lewy Buddy responds to requests to the Lewy Body Dementia Association from people seeking information about LBD.

Paula: That's it exactly. I help respond to emails and phone calls from folks seeking local resources for the midwest region of the USA.

Ann: Can you share with our listeners how they can get connected to the Lewy Body Dementia Association?

Paula: Great idea! To get help visit www.lbda.org and go to their Support section or call the LBDA Lewy Line at 1-800-539-9767. That number again is 1-800-539-9767. You can also visit their website at www.lbda.org.

Linda: That's actually how Paula and I met. I'm Linda Olsen Engel and Paula answered my initial call to the national LBDA hotline.

Ann: Interesting, Linda.

Linda: Isn't it, Ann? My husband had just been admitted to the hospital, where he was diagnosed with "probable LBD." We were shocked because mere days earlier a neurologist had insisted we were not dealing with it.

Paula: That's part of what's tricky about this disease: fluctuations in cognition and behavior can make it so difficult to diagnose.

Linda: It's completely unpredictable. Anyway, given what was happening with him physically and mentally, the hospital doctors and nurses told me that it would not be safe to bring him back home.

Ann: What happened after you got that news?

Linda: That's when I first called the LBDA hotline and ended up speaking with Paula. Paula, you were such a tremendous help! Not only did you calm me, but among other supportive information, you told me about the LBD Caregiver Support group monthly meetings in the Twin Cities metro area. The very next month I drove down from where I live in central-Minnesota, to the support group location in Maplewood which is roughly a two-and-a-half-hour drive one way.

Paula: I remember that night when you came to your first meeting.

Linda: The group was an amazing lifesaver that night. Actually throughout our family's entire journey that group helped us navigate continuous and rapidly occurring crisis points.

Paula: Thanks, that's good to hear.

Linda: Well and as you know Paula, even after my husband passed 10 months later, I continued to make the 5-hour round trip drive to stay connected with this group. Then in 2020, due to COVID, the group stayed connected via Zoom, so I was able to attend without the big drive.

Ann: Linda, your willingness to make that drive is amazing. It's a true testament to just how difficult it can be in some communities to find an LBD support group.

Linda: Yes, getting connected to the right people and the right resources can be a challenge, especially when you're reeling from the emotional impact of a LBD diagnosis.

Paula: Currently both of my support groups are still meeting using Zoom. We found that many people like not having to leave home in order to attend a meeting. We are looking at perhaps meeting in person once a month and meeting via Zoom once a month.

Linda: That sounds like a great plan, Paula. By the way, before we go any further, listeners should know that stories and situations shared in the support groups and via the help line are all confidential. This is an important thing to know — support groups are based on this trust.

Paula: Any stories that we share in this podcast series are stories that we've been given permission to share.

Ann: Now Linda, why don't you tell us a little more about your personal background?

Linda: Sure, Ann, thanks. After adopting 2 children in 1991, I took a leave of absence from working in the public schools as a speech/language pathologist/coordinator. During my working years, I had organized local and state level professional meetings in the field and branched out to present sessions at women's workshops in the community. Some of my essays and interviews have been published in magazines and books.

Ann: I know, because you've shared some of them with us, that you took extensive notes during your late husband's illness. Your background as a writer must've really helped.

Linda: I think so, plus I've always kept journals so it seemed like a natural thing to do.

Ann: As you know, I like writing as well. In fact, I work as a corporate communications consultant.

Paula: And your experience in that field is what really brought about this podcast.

Ann: Yes, I saw a gap in the information people wanted to have about LBD and the information that was readily available. I occasionally listen to podcasts and one morning when I was listening I thought maybe a podcast format would be ideal to reach caregivers because they can be so short on time. They can listen to this information

while they are driving in their car, taking a walk, cleaning their house, running errands. I called Linda and she thought this was a great idea. Then I called you, Paula, and our podcast team was born.

Linda: That was so insightful, Ann! So, what about your personal background, Paula?

Paula: I was a programmer analyst for the Minnesota Secretary of State's office and when we converted from our legacy system, I wrote technical documentation detailing the requirements for various applications. Those analytical skills ended up being really useful when advocating for my Dad. I was able to look at various issues that came up with his care and parse out what steps needed to be taken to get him the help he needed.

Ann: It's interesting how we all are using different skills we've picked up along the way to help with this podcast project.

Paula, let's now shift back to the topic of Lewy Body Dementia and talk about what it's like right after getting a diagnosis. How do people react to this news?

Paula: It really varies depending on individual circumstances, especially since most people have never heard about it before. Many are relieved that there is finally an answer to why things haven't been going well.

Ann: Yes, there's a sense of relief but it is mixed with a sense of absolute dread. Because no one would ever wish an illness like this on anyone, right? It makes this news very difficult to hear.

Paula: Yes, it does. One of the most common concerns following an LBD diagnosis — and a topic that repeatedly surfaces during support group discussions — is the lack of real life follow through.

Ann: What do you mean?

Paula: Many people have told me "The neurologist spent a lot of time discussing tests and test results and the diagnosis, but little to no time discussing what to do next — aside from telling us to come back in six months."

Ann: What happens in these situations?

Paula: It leaves the person who has received the LBD diagnosis — and those who are caring for them — wondering "How do I deal with these symptoms?" — "How do we prepare for what lies ahead?" — "Where do we go for more information?"

Linda: Well, if you're comfortable searching the web, you can locate a lot of technical medical information. And the good news is that there's more and more general

information about LBD becoming available all the time. But it's not easy to find personal information about what it's like being down in the trenches, actually navigating this disease as a caregiver.

Ann: Yeah, there still isn't a lot of public awareness. Even though Lewy Body Dementia is the second most common form of dementia, it is the least understood and the most difficult to diagnose because it's so episodic in nature.

Linda: Exactly. Most people know what Alzheimer's and Parkinson's are, but chances are they don't know what Lewy Body Dementia is until it affects someone close to them. Alzheimer's is associated with memory loss, Parkinson's is a movement disorder, but LBD doesn't have one single distinguishing symptom that can be used to describe it. It has clusters of symptoms, and not every person experiences the same cluster.

Paula: Yeah, and unlike other forms of dementia where decline continues on a steady downward pace and the disease progresses in distinct stages, the cognitive abilities of a person with LBD ebb and flow. It's very unpredictable and an individual's abilities and symptoms may vary by months, weeks, days or hours — sometimes even minutes!

Ann: I think that's what makes it so tricky.

A person may be able to do math — for example, balancing a checkbook or writing a check to pay a bill one week, have troubles with it the next week, and later on be able to do it more easily again.

They can do tasks like taking out the garbage or putting away the dishes or can pick an item from a menu with no problems on some days but not on others.

Linda: Or they know how to use a fork and knife during lunch, but during supper they can't figure it out. Then they are fine using utensils the next day.

Ann: Often, it's hard to understand that something is wrong when symptoms are so varied and when they come and go. So, how do you know when it's time to visit a neurologist?

Paula: Based on the conversations in my support groups, the realization that a visit to the neurologist needs to take place comes about in a variety of ways.

Some people notice small little things, like the ones Ann and Linda just mentioned, that just happen more and more often until they can't be ignored.

Other times it's a health problem involving a hospital stay or a surgery that causes issues the patient was able to subvert to come to the surface. They can't hold onto their "normality" any longer because their inner reserves are depleted.

For others it's a sudden onset of symptoms — a big crisis, like Linda and her husband experienced.

Linda: That's right, and I should mention that our situation was more alarming than most. With LBD, every journey is unique. By attending support meetings and joining Facebook caregiving groups, I learned how mysterious, variable and unpredictable Lewy can be.

Ann: So, given how common it is, why is it that so few people know about it?

Paula: One of the reasons is that LBD is a relatively new diagnosis. Also, it's only more recently that higher profile individuals like Robin Williams and Ted Turner and their families are going public with an LBD diagnosis, increasing awareness of the disease.

Ann: Paula, you are so well versed in the history of this disease, why don't you share some of the details. It's helpful to know where the discovery of this illness began and what's happening now.

Paula: Sounds good.

The LBD story starts back in 1912 when Dr. Frederic Lewy was working with Dr. Parkinson in Dr. Alzheimer's laboratory in Germany and discovered what are now called Lewy bodies.

Ann: And what exactly are Lewy bodies?

Paula: Lewy bodies are alpha synuclein proteins normally found in the brain, but also in other nerve cells, which have become misfolded and altered from their usual state. No one knows to this day why this happens.

Linda: How did Dr. Lewy happen to discover those abnormal proteins?

Paula: He was studying the brains of persons who had died of Parkinson's disease when he found these misfolded proteins — what we now called Lewy bodies. It was then determined that Lewy Bodies occurring in a certain area of the brain were connected to Parkinson's disease.

Ann: Interesting.

Paula: But the connection between Lewy bodies and dementia wasn't discovered until long after Dr. Lewy's death.

Ann: And how did that happen?

Paula: Decades later — in the 1960s and 70s — autopsy reports began showing Lewy bodies in the brains of patients with cognitive symptoms but no Parkinsonian symptoms. And they appeared in other parts of the brain, not just in the motor area like with Parkinsons.

Ann: Paula, didn't you tell me that this type of dementia was still thought to be extremely rare until a method of staining Lewy bodies during brain autopsies made it easier to detect them?

Paula: Exactly. And it wasn't until the late 90s that dementia associated with Lewy Bodies even got named as a separate disease.

Ann: It's amazing that it took that long, really?

Paula: Yes. In 1995, Lewy body researchers from the United States, the United Kingdom and Japan held the first International Lewy Body Conference. A consortium that was formed at the conference, agreed upon the term Dementia with Lewy Bodies the following year and defined the first set of criteria for diagnosing it.

Linda: Hmm, I'm finding an interesting correlation here. About the same time as the consortium you mentioned, Paula, smart phones and internet communications were becoming more available to the public which enabled better sharing of information. In fact, I remember reading how post mortem autopsies, combined with reports from families who compared loved ones' behaviors, demeanors and cognitive issues actually helped define differences between Alzheimer's and Lewy Body behavior markers.

Paula: You're right, Linda. Families started having the ability to more easily find information about new medical discoveries. And they could share their own observations with one another in ways that weren't possible before then. I think you are right that scientific research greatly benefited from the ability to more easily share data and gather observations from caregivers.

Linda: Makes sense but it certainly took a lot of decades from when Lewy Bodies were first discovered to when Lewy Body Dementia was recognized!

Ann: Paula, I'd like to go back to something that you mentioned earlier. You said that Lewy bodies are alpha synuclein proteins that become misfolded and altered from their normal state. What happens when this occurs?

Paula: In the brain, alpha synuclein proteins are found mainly at the tips of nerve cells. But no one is quite sure exactly what the purpose of alpha synuclein is.

Linda: Really? That's interesting.

Paula: Yeah, we know that when neurotransmitters are released into the gap between nerve cells, that is how messages are passed from one neuron to another. When alpha synuclein proteins mutate into Lewy bodies, they can block this normal messaging process between neurons.

Ann: In other words, the presence of Lewy bodies in the brain affects the brain's ability to send and receive messages correctly. And, if I understand what you're saying, it's where the Lewy bodies are located in the brain that determines what kind of symptoms happen?

Paula: Yes, that's also why one person living with LBD can exhibit very different symptoms from another person with LBD.

Some have mild symptoms in one area, others have moderate or severe symptoms.

And symptoms change, they come and go. Unlike other diseases with predictable stages, people with LBD and their care partners have to expect the unexpected.

Ann: That's tough, really tough.

Linda: Yeah, it is. Okay, so we know why there are so many different possible symptoms, but do doctors know why the fluctuations happen?

Paula: No, it is a big mystery why persons living with LBD can swing from extreme difficulties with cognition to being able to operate on a higher level of functioning again. Researchers are still trying to figure this out.

Linda: Well I hope for everyone's sake they figure it out sooner than later! Could it be because neurons are regenerating after they get damaged due to Lewy Bodies forming?

Paula: No, researchers don't think that is what is causing the fluctuations. Neurons can't recover that quickly. These changes in cognitive ability can happen over very short periods of time. And with LBD they don't see a lot of brain degeneration as compared to Alzheimer's. The symptoms seem to have more to do with how neurons communicate with one another. There are just not that many theories about why the symptoms fluctuate so much for persons with LBD.

Ann: Well, as Linda just said, for everyone's benefit, I hope they are able to figure that out soon!

Let's shift our conversation now and talk a little bit about the diagnostic criteria for LBD. Paula, what do doctors look at to determine whether someone has LBD?

Paula: Sure. The most recent set of criteria was published in 2017. First and foremost, dementia must be present. Dementia is medically defined as a "progressive cognitive

decline of sufficient magnitude to interfere with normal social or occupational functions, or with usual daily activities.”

Linda: But doesn't that create a problem, since dementia isn't always present early in LBD?

Paula: Exactly. This means that sometimes a diagnosis isn't possible until people have experienced a lot of the other issues associated with LBD. We'll talk about those early symptoms and problems in our second episode.

Ann: Yes we will. In addition to dementia, what are the other criteria?

Paula: There are four core clinical features besides dementia. Not all of these symptoms need to be present though. A person only needs two or more of them, in addition to dementia, to be diagnosed with probable Lewy Body Dementia.

The first criteria on the list is fluctuating cognition — large variations in attention and alertness.

Ann: And how do these large variations in attention and alertness get verified or documented? How do you test for fluctuation?

Paula: Reports from care partners and families play a huge role in capturing this as a symptom.

Doctors can test for decline in various areas using neuropsychological tests and people will show fluctuation in those results — lower and higher abilities — but that is over the years as these tests are repeated. Doctors must initially rely quite a bit on the patient's reported history.

Linda: Yes! The people who notice these cognition changes first are going to be close family members and friends. And they may notice symptoms long before the decline is significant enough to show up in the neuropsychological test results.

Paula: Right. But fluctuation is a hallmark of Lewy Body Dementia so it is important to evaluate whether someone is steadily declining or has that up and down roller coaster sort of cognitive experience.

Ann: So, fluctuations are the first core criteria. What's the second core criteria?

Paula: The second one is recurrent visual hallucinations that are very detailed and realistic. Seeing children or animals that aren't there is very common.

Ann: But, not all people with LBD have hallucinations, correct?

Linda: That's true, Ann, not everyone does.

Paula: My dad did though. I remember visiting my dad once when he started talking to two good friends of his that suddenly appeared to him. He told me that they were really small, like about a third of their normal height, and that confused him. He was happy to see them at first, but got frustrated when they wouldn't answer him when he talked to them.

Linda: Whoa, Then what happened?

Paula: My dad followed them as they moved from his living room towards his bedroom closet, where they disappeared.

Ann: How did he respond to that?

Paula: Well, this irked him. He said "To heck with you guys then!" He clearly saw those two friends and even though they were miniatures of themselves and wouldn't talk to him, they were real to him. He didn't understand why we couldn't see them.

Linda: Like your dad, Paula, my husband did have hallucinations.

Ann: My grandpa also had them. He saw children playing in his backyard and would call to my grandma to get the children out of the yard. But there weren't any children there.

Paula: People with other types of dementia also have hallucinations, but usually not until the later stages. With LBD it can be one of the earlier symptoms. Sometimes people recognize that they are having hallucinations, sometimes they don't. But again, not everyone with LBD will have hallucinations.

Ann: So far we have fluctuations and hallucinations. What's the third criteria doctors look for?

Paula: The third criteria is REM Sleep Behavior Disorder or RBD. And the fourth one is Parkinsonian symptoms, for example, slowness of movement, a rest tremor, rigidity, or a shuffling walk.

Ann: Can you go back and explain the third one for listeners who aren't familiar with that — REM Sleep Behavior Disorder — in more detail?

Paula: Yeah, sure.

Typically when we sleep, our brain actually paralyzes our body while we dream. Our eyes still continue to move though. REM stands for Rapid Eye Movement. And we can still breathe of course, but everything else is kept still during this stage of sleep.

With REM Sleep Behavior Disorder, or RDB, this process no longer works. Instead people act out their dreams, yelling, thrashing, punching, kicking, and things like that.

Linda: That explains a lot: My late husband exhibited these behaviors for years, but refused to have a sleep study. This was frustrating for me because I had learned that one of the things to look for was REM sleep disorder.

Paula: Yeah, a sleep study allows doctors to actually see the distinctive brain wave patterns that indicate this disorder during REM sleep. That said, a sleep study is just a snapshot in time. So, it's good to keep a journal if you have a bed partner that might be acting out their dreams so this information can be shared with his or her neurologist.

Ann: We are coming back to the importance of taking notes. And I think we will discuss this again and again in future episodes. Linda, did your husband know he was acting out his dreams?

Linda: Actually no, Ann. He was in total denial about all of his symptoms including his disturbed sleep. When he began punching me in the head, though, I had to start sleeping in separate quarters. Others have reported similar experiences.

Paula: The person who is acting out the dreams may not remember it unless they are moving so much that they wake themselves up!

Ann: Paula, what about your dad?

Paula: He did know that he was acting out his dreams because he would wake up due to his very violent reactions. My Dad was actually one of the first ten people diagnosed with REM sleep disorder back in the 1980s when the syndrome was first being researched.

Linda: Really?

Paula: Yes, the research about this disorder was actually pioneered in Minnesota. I had read an article about a study taking place of people acting out their dreams in one of those commuter newspapers that you could pick up in downtown Minneapolis where I worked. I think it was the Skyway News.

Ann: I remember the Skyway News.

Paula: Well, I brought the issue home to show my parents, who were in their mid-fifties at the time, because my Mom had told me that my Dad was punching out in his sleep and would sometimes actually hit her. They were thinking of going to marriage counseling or to a psychiatrist to figure out what was going on with my Dad.

Ann: Oh, wow!

Paula: He was diagnosed pretty quickly and ended up being patient #8 in the various research papers that were published about REM sleep behavior disorder.

Ann: Once they diagnosed it, were they able to treat it?

Paula: Yes, Ann, very successfully. Back then they used L-Tryptophan.

Linda: L-Tryptophan: isn't that the chemical in turkey and other foods that makes you drowsy?

Paula: Yes, it is. And it worked like magic!

They had no idea though that this syndrome had anything to do with developing LBD or Parkinson's Dementia.

My Dad's sleep doctor and researcher, Dr. Schenck, later contacted our family to see how Dad was doing. This was right around the time my Dad was hospitalized in 2008 due to a sudden downturn caused by taking a medication. At the time he wasn't diagnosed with LBD — he was thought to have vascular dementia. He had been having cognitive issues since 2003.

Linda: Wow, so it was like 20 years or so later after having REM Sleep Behavior Disorder that your Dad developed dementia or showed signs of dementia?

Paula: Yes. Some people who were in the research back in the 1980s were starting to report issues with dementia, which is why Dr. Schenck and Dr. Mahowald started contacting everyone to follow up.

Ann: That's really interesting. And it's important to note how much time may pass between an REM Sleep Behavior Disorder diagnosis and an LBD diagnosis.

Paula: Yes. Dr. Schenck then referred my Dad to Dr. Boeve at the Mayo Clinic in Rochester, who was working with Dr Schenck to determine if there was a connection between REM sleep behavior disorder and particular types of dementia. And now it is considered a core clinical feature of LBD! My Dad had a part in that.

Ann: That's quite the history! It just goes to show that medical discovery and understanding takes time.

Linda: So to sum things up, for diagnosis you look for those four core clinical features, Fluctuation, Hallucinations, REM sleep behavior disorder, and problems with physical movement, the Parkinsonian type element. And you need to exhibit at least 2 of these, plus dementia, to be diagnosed?

Paula: Yes that's right. But it's a little more complicated than that, they can look for certain biomarkers too. Biomarkers are objective indications of a medical condition — something can be measured accurately and reproduced in multiple tests.

Ann: And what are those biomarkers they look for?

Paula: Well, they can do a scan to determine whether there is reduced dopamine uptake in the basal ganglia.

Not all persons with LBD have problems in this area of the brain, but many do. It's also an area of the brain that is not affected early on in persons with Alzheimer's disease.

Linda: So you said biomarkers — I assume there are others?

Paula: Yes, two other ones are used right now. The test results from a sleep study indicating REM sleep disorder is considered a biomarker. And the third biomarker is detected by a cardiac scan that is commonly used in Japan to diagnose Lewy Body Dementia. The scan determines whether there is nerve damage to a certain area of the heart that is known to be caused by Lewy bodies. This scan is currently used in the United States to diagnose other diseases, but not LBD.

Ann: So, is it in the works to start using cardiac scans to help diagnose LBD in this country?

Paula: Not in the US. Remember, the diagnostic criteria for LBD is international in its scope. In the US, researchers are looking at examining spinal fluid using lumbar punctures. This is more invasive but it is thought to be more accurate. A test to detect actual Lewy Bodies in the spinal fluid was approved for use by the FDA for research purposes. There is also a skin test that is being used in research that can detect the presence of Lewy Bodies in the nerves of skin tissue. Those two tests aren't used in clinical diagnosis as of early 2022 but that could change soon.

It is hoped that eventually we can come up with a test that will enable us to make a definite diagnosis — not just a probable diagnosis — while people are still alive instead of waiting for a brain autopsy to confirm the presence of Lewy bodies.

Ann: Well, that would definitely be helpful — for both people exhibiting symptoms and for those that are living with them or providing care.

Linda: Indeed!

Paula: Yeah, right now we can look for symptoms and for biomarkers but nothing except a brain autopsy can say for sure that Lewy Bodies are present in the brain. We're getting really close though now, really close.

Linda: So doctors look for dementia, plus those four core clinical features and for these three biomarkers — what’s required then to actually make a diagnosis?

Paula: For probable LBD you need to have dementia, plus two or more core clinical features with or without the presence of those biomarkers.

If you have only one core clinical feature but have one or more biomarkers, that’s also considered sufficient for probable LBD .

The 2017 Diagnostic Criteria also goes into what is used to diagnose possible vs probable LBD and talks about counter—indications that can steer the doctor away from a diagnosis of LBD.

Ann: So, In a nutshell, it’s pretty complicated. At the end of the day, I think what’s important to know is that LBD can be hard to diagnose for a host of reasons. And, even though it's the second most common form of dementia, unlike Alzheimer’s Disease, a lot of people haven’t heard of it.

Linda: Right on, Ann! Just recently it has been noted that Lewy Body Dementia is “the most common dementia that you’ve never heard of.” That was certainly true in our situation. My husband’s family had a history of Alzheimer’s Disease. So, when I noticed he was experiencing depression, apathy, detachment, anger and becoming hostile as well as verbally abusive, I had confusion added to my concern.

Paula: Well, that’s understandable.

Linda: Yes, so around 2007, I attended an AARP free lunch seminar in Park City, Utah. The topic was healthy aging and I chose to attend one session on “brain aging.” The speaker said that hereditary Alzheimer’s Disease typically shows up during the same decade in each generation. The people in my husband’s family with Alzheimer’s started showing signs in their 60s. My husband was almost 60, so I began to study and learn what I could.

Ann: So, did you do this on your own, or with the help of others?

Linda: A bit of both, really. Fast forward 5 years later to 2012. While attending an Alzheimer's support group back home in Minnesota, one of the group leaders shared that her husband had been diagnosed with Lewy Body Dementia. NO one in the group had heard of that form of dementia before. But as the leader described its characteristics, I had a chilling epiphany that we could be on this “roller coaster.” Then, a friend whose spouse had Alzheimer’s pointed out how her husband stayed on plateaus for a while and then would slip down into another plateau, stay-there and eventually lose even more skills, never gaining ANY back. In comparison, my husband would lose and regain skills.

Ann: So what do you think a person in this type of situation should do?

Paula: If you don't have a diagnosis yet, but sense something is not right, the best advice I can give and that I have heard doctors give, is take notes.

Include the date, time and a description of what's happening — whether it's cognitive, behavioral, sleep related or movement related. Then bring these notes with you to the neurology appointments.

And if you have a diagnosis and are struggling with how to manage symptoms, it also helps to take notes. This can help the doctor determine if there are medications that can alleviate these symptoms.

Linda: Excellent point, Paula! That's exactly what I started doing in 2007. As mentioned earlier, I've always kept journals. But, logs don't need to be detailed: sometimes I merely made quick notations on pocket calendars, or on my phone. 10 years later those cumulative notes helped the hospital team reach the probable LBD diagnosis.

Paula: One other important note about diagnosis. One of the supportive symptoms that gets mentioned is severe sensitivity to antipsychotics.

Linda: Don't people with LBD have very individual reactions to those types of medications?

Paula: Yes, it makes treatment something that needs to be done very carefully, starting with an extremely low dose of medication and increasing it very slowly to see what the effect is. Start low and go slow is the motto that's used when starting LBD treatment..

Ann: Also, sometimes drugs that are used to help with hallucinations, delirium and agitation can cause reactions in people with LBD that are the opposite of what is intended — they can become more agitated rather than less so.

Paula: You are right, Ann. They can also be overly affected by a drug and need a much smaller dose than is usual.

If I could change one thing about how people with dementia are treated in the Emergency Room when they are brought in due to mental or emotional crisis, it would be to stop medical staff from automatically reaching for Haldol as the go-to drug. I have heard countless stories of horrible consequences caused by giving this drug to someone with LBD.

Ann: What happens to them?

Paula: They can become comatose to the point where their life is endangered and recovery is doubtful. The Lewy Body Dementia Association's Scientific Advisory Council advises NO Haldol! Up to 50% of people with LBD will react very poorly to this drug.

Ann: That's one out of every two. That's a high percentage!

Paula: Yet it is still common practice in the ER. My Dad's own diagnosis was supported by his reaction to a newer antipsychotic drug that was being tried to help deal with his inappropriate behavior. It was a disaster that landed him in the hospital for a week and then in a nursing home for eight more weeks.

Ann: How awful.

Linda: It certainly is awful! Okay, so there are lots of challenges to deal with here: the fluctuations are hard to understand, the disease is unpredictable as to what symptoms might occur, and then drugs that can be given to other dementia patients in crisis COULD end up not only being ineffective but can actually be dangerous for people living with LBD.

Ann: That's a lot for caregivers to take in and for persons living with LBD to experience. I can see why the disease is called a roller coaster — you are dealing with ups and downs and often you can't see what is beyond the next corner!

Linda: I think it helps though to know that this is the nature of disease and that we aren't imagining things. The person really can be unable to do something for a period of time and then regain their ability to function almost normally.

Ann: They aren't just faking it or trying to get attention — that's how the disease works.

Linda: It is. Well, it's about time for us to wrap up this episode.

Ann: Yes, do either of you have any final thoughts?

Paula: I'd like to end this episode on a positive note.

Although medication can be troublesome, there are drugs that can help, in fact some drugs initially developed for Alzheimer's actually have been shown to be even more effective for LBD — drugs like Aricept and Exelon.

And new research is focusing on potential treatments that will address the nature of the disease and not just the symptoms.

Also, with LBD it is thought that there is less degeneration of neurons than in other dementias, that the symptoms have to do more with chemical imbalances and blocked neuronal pathways. So there is hope for potential recovery if we can find a treatment!

Linda: And because LBD does fluctuate, we can make use of the good times and improved abilities to plan for the future and do things we enjoy doing. We do hope our podcast series will help listeners learn how to navigate both the good and the bad times.

Ann: Thank you for joining us today. For more information and a list of the resources discussed in today's episode, please visit our website at www.lewybodylife.com. And, if you enjoyed this episode, please be sure to check out the other episodes in our series.

Linda: Good idea. If you know someone who may benefit from hearing our discussion today, please forward this podcast on to them!

Paula: In this first episode we covered a lot of territory. After all, we called it Lewy Body 101! In our future episodes we will be concentrating on more specific topics. Our next episode of Lewy Body Life is "Hindsight is 20/20: Early signs of LBD" We hope you can join us!

Ann: In the meantime, support is available from the LBD Association's Lewy Line at 1-800-539-9767. Thanks for listening! And have a great day!

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