Season 2, Episode 2: Ready, Set, Go: Planning for Medical Emergencies

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

Paula: I'm Paula Rice Biever.

Linda: And I'm Linda Olsen Engel. Thank you for joining us for today's episode: "Ready, Set, Go: Planning for Medical Emergencies."

Paula: Before we get started, we'd like to give a shout out to the Rochester Mayo Clinic for including our podcast series on their Dementia Hub online resource and also to the Minnesota Department of Health for featuring our podcast in their Healthy Brain Initiative newsletter.

Ann: Yes, we're grateful for their interest in our series and for helping us spread the word! As of January 2026, our podcast has been downloaded over 10,000 times.

Linda: It feels good to know that our experiences are helping others on their LBD journeys!

Ann: It sure does! We're also excited to share that the Kissick Family Foundation is featuring our podcast on their new Beyond Memory website at www.beyondmemory.org!

Paula: We'll feature a link to this site on our Resources page for this episode. The Beyond Memory website is about dementias other than Alzheimer's, in which memory loss is not the primary symptom.

Linda: We also want to thank the listeners that have taken time to review our podcast on Apple and Spotify. Your feedback is inspirational and means so much to us!

Paula: We realize that it's been quite a while since our last episode. Life has been complicated for us, but things have calmed down and we're eager to get back to it.

Linda: In our previous episode, we discussed how to protect yourself if LBD behavior becomes violent.

Ann: Today, we're talking about another type of crisis — medical emergencies — and how to prepare for and respond to them.

Paula: Whether it's an emergency that involves you or the person with LBD that you're caring for.

Linda: Yes, being prepared for a possible medical crisis can help you respond quickly and get the assistance you need.

Ann: Before we go any further, we want to remind our listeners that our podcast is for informational purposes only and does not constitute medical, legal or tax advice. You should always seek advice from the appropriate professionals for your specific situation.

Linda: Good point, Ann.

Ann: So, Paula, where do you think we should start?

Paula: Let's start by acknowledging that being a care partner is extremely demanding. When you're under the day-to-day pressure of that role, it's hard to carve out time to do more, to prepare for the future. But taking the time to prepare for medical emergencies can help lessen stress and lead to better outcomes — for you and the person with LBD.

Linda: Agreed, but how do you begin? What's most important to do first?

Ann: That depends on your situation. And that's why we've broken today's episode into five key topics. As you listen to this episode, you can decide what's most important to you. You don't need to get everything done all at once.

Linda: We'll start by talking about creating medical history documents and an emergency contact list.

Ann: And then we'll discuss how to summon emergency assistance and things you can do to make ER and hospital visits more successful.

Paula: And last but not least, we'll cover the critical legal documents that you need to have in place so you can care for and advocate for your person.

Linda: Paula, why don't you start with our first topic, creating a list of documents with important medical information.

Paula: Okay. You want to start by creating one set about the person with LBD who you are supporting and another set of documents about yourself.

Ann: You know**,** while we were preparing for this episode, I read a *New York Times* article titled "Paramedics Share One Tip That May Save Your Life" and it's all about making sure you have your medical information well documented and readily available — exactly some of the things that we're talking through today.

Linda: Really? How timely that this article should come out just while we're putting together an episode about this very subject!

Ann: Yes, it is — and it reinforced the importance of carving out time to organize this information.

Linda: So, let's talk about what each set of documents should include.

Paula: Each set should contain two different documents. The first document covers medical history and should include a list of your doctors — or the doctors for your person with LBD. It should also list individual health conditions and concerns, and other important information.

Ann: Like your medical insurance details.

Paula: And which hospital you prefer.

Linda: Hmmm… The second document will be a list of medications that you — or your person — are taking.

Paula: When I was caring for my dad, who had LBD, I always kept a separate list of medications because sometimes that's all I needed. And that made it easy to update his medications list when my dad started taking a new drug or stopped taking an old one.

Linda: I didn't do a great job with the list of medications when I was caring for my husband because I was so overwhelmed. Looking back this would have been a very helpful thing to have done.

Paula: Linda, it's hard to do all this when you're in the thick of things. But just getting started with making these lists can help. And then you can return to them when you have five or 10 minutes to work on the lists until the task is done.

Linda: Thank you, Paula! While talking through this, I'm realizing that I could have enlisted a trusted family member or friend to help me with this sort of task.

Ann: Great idea, Linda. Sometimes having help can make a project like this so much easier — and even a bit enjoyable.

Paula: It sure can.

Ann: So, let's get down to the details about the medical history document. It should include four parts. The first part is the doctors' and health providers' names, their specialties, their contact information and their office names and addresses.

Paula: The second item to include on the list is what hospital or medical center you'd want to be taken to in case of an emergency.

Linda: Yes, and sometimes your insurance will determine where you can go, so check that out too.

Ann: And speaking of insurance, the third type of information to list on the medical history document is your insurance information.

Paula: And the fourth item is the medical conditions that you and your person are currently dealing with. If you've had surgeries in the past or medical issues that have been resolved, list those as well.

Linda: We realize this is a lot of information**.** We suggest you begin with the basics and then add in more details. Get those doctors listed and state what hospital would be appropriate in case of an emergency. You can fill in the rest as time permits.

Paula: And for those of you wanting further guidance about creating a medical history document, we've included a link on our website, LewyBodyLife.com to a template for documenting health information that might be helpful for you.

Ann: Yes, and we've also included a link to the *New York Times* article I mentioned. You can find this information on our Resources page.

Linda: And keep in mind that we have transcripts for all our episodes on LewyBodyLife.com. You can print the transcripts, which may be easier than taking notes about all this.

Paula: Yes, the transcripts are a great resource.

Ann: So we've talked about what the medical history document should include. Now, let's cover what the second document — the list of medications — should include.

Paula: That list should state the name of the medication; why it was prescribed; the name of the prescribing physician; the start and stop dates; and the dosage amounts.

Linda: If you're not sure why a medication was prescribed, be sure to find out and include that information on the list.

Paula: Yes, that's important. This concern comes up frequently in my support groups; sometimes people realize that they don't recall why a medication was prescribed.

Ann: Even if a medication is discontinued due to a reaction, or replaced by a different drug that works better for you or your person, have that history documented — so you know why a certain drug is no longer being used or shouldn't be prescribed.

Linda: This is especially helpful if you switch doctors or end up in the hospital. They need to understand why you or your person are taking one medication instead of another.

Ann: And again — you can start out by simply listing current medications and dosages. Add the historical information as you have time. And when something new gets prescribed, add it to the list. I was in a pinch the other day and I just lined up the medications on the counter and snapped a picture with my phone so I had the names of the medications and the dosage amounts to share with the doctor.

Paula: And for medications that are prescribed to help with cognitive symptoms, I suggest including a section for notes so that you can document how well a medication has — or hasn't — worked and any side effects that are being experienced. That can be really valuable information for upcoming doctor appointments as well as for medical emergencies!

Ann: These are all great recommendations. Last year, I experienced firsthand how being prepared can make a big difference when I had to call 911 on behalf of my dad. He doesn't have LBD but he did have a medical emergency.

Linda: Oh Ann, how stressful!

Ann: It was. And when the EMTs arrived, the first questions they asked were what his health issues were and what medications he was on.

Paula: That's typical. But if you haven't had a medical emergency before, you likely wouldn't be expecting or be prepared for those questions!

Ann: Agree! So thankfully, my mom had a document that listed his current and past medical conditions and his surgeries — and another document that listed the medications he takes and their dosages — all on her computer. She was able to quickly print these documents and hand them to the EMTs, who were extremely grateful. And because the lists were printed — not hand-written — the EMTs could quickly and easily read them.

Linda: That's awesome, Ann! Actually, it might be helpful to print copies beforehand so they are readily available when an emergency occurs.

Paula: Yes, it's especially important to have a current medication list and schedule readily accessible at your home. Keep it on your counter, fridge, or kitchen table.

Linda: Right, because if something happens to you, you need that information to be available to whomever might take over temporarily to care for your person.

Ann: Good point, Linda. In addition to keeping copies of this information at home, consider keeping copies in your vehicle, your purse — or another convenient location — in case an emergency occurs while you're away from home.

Paula: I remember an incident with my Dad. His care residence called me because he had dialed 911 and had been taken to the emergency room. I had to get to the hospital quickly and was utterly exhausted because my Dad had been having problems for several weeks.

Ann: As anyone who has been in an on-going crisis knows, it's exhausting, which makes it all the more difficult to think clearly and to function well.

Paula: It does! When I arrived at the hospital, the staff asked me what medications my dad was on — even though I knew they had all that information in their system because he'd just been discharged from that hospital the previous week! I'm usually very prepared but that day I wasn't and — when they wanted me to recite that information all over again — I was so frustrated that I burst into tears.

Linda: Oh Paula, how unsettling. You know, your experience shows how being prepared for an unexpected trip to the ER isn't just a good idea logistically, it's also something that'll help you cope better in a stressful situation.

Ann: So true! And these examples just reinforce how documenting your medical information benefits everyone involved in a medical emergency.

Linda: So, now that we've covered our first topic, creating medical history documents, let's go on to our second topic, making an emergency plan.

Paula: An emergency plan covers what to do in the event of a crisis — who to contact and what steps to take to make sure essential things get done. It's helpful to involve family members, friends, and neighbors when you are making your plans, so they know how to step in to care for things if either of you have a medical emergency.

Linda: Having a plan is definitely helpful — not just for medical — but for other types of emergencies as well.

Ann: So true Linda! I also want to mention that when you're a care partner, it's easy to become so focused on what needs to be done every day that you become isolated from your neighbors and don't see or talk with your family members and friends as often as before.

Paula: It’s important to work against that tendency. Reach out — and make an effort to stay connected. And, when asked, be honest about your situation. Sharing this information will help you feel more supported and make things easier if you end up needing to call on these people in a crisis.

Linda: That’s a huge point, and this is something that I think I did do well. I reached out to my neighbors and friends to stay connected and grounded and it really did help.

Ann: That’s good to hear, Linda. Sometimes, it’s easier to remember the things we didn’t do as well as we wished, instead of the things we were successful at. I think everyone does the best they can on any given day.

Linda: Uh-huh.

Paula: When you’re planning for emergencies, think about what might need to be done if you weren’t able to do anything for a period of days. And then identify the people in your family and social circles who might be willing to step in and help if needed.

Ann: For example, a family member may be willing to step in to care for your person if you are in the hospital, a neighbor may be willing to mow your lawn or help with snow removal — or even bring in your mail. Others may be willing to pick up incidentals, drop off home-cooked or takeout meals, or help out with laundry and other needs.

Linda: So true, and you know, these sorts of arrangements are best done early on when you have more time and the opportunity to make appropriate plans. But sometimes it takes a crisis before you realize just how important it is to have contingency options like these.

Paula: That’s so true, Linda! And again remember to start out with the basics. First figure out who should be contacted in case of an emergency and make sure to have their contact information. You can then work on expanding your emergency plan and maybe set something up like a notification tree — also known as a phone calling tree.

Ann: Yeah, you contact one or two people, who then notify others on your contact list about the emergency, and what has happened. They may end up contacting additional people depending on what arrangements you’ve made and what the situation is.

Linda: Another great idea, Ann. A notification tree spreads out the responsibilities so that one person doesn’t have to contact everybody. People can have an agreed upon task or assignment that they know to do if they get the call!

Paula: Remember, you don't need to figure everything out all at once as to who will do what. You can work on your ideas and plans, knowing that you've got something set up as to who should be notified in case of an emergency.

Ann: So, Paula, what else can our listeners do to prepare for a medical emergency? What else should be part of their emergency plan?

Paula: Well, if you — the care partner — are the person experiencing the medical emergency and need to call 911, be sure to state that you're responsible for a vulnerable adult, someone who cannot be left alone.

Ann: That's critical if you don't have back up help like we just described, then a hospital social worker can assist in making temporary respite care arrangements.

Linda: Another thing to keep in mind is that if you get injured or become ill, your person may not be able to help you or to understand the seriousness of the situation. An example of this is what happened with Gene Hackman and his wife!

Paula: As soon as I heard that Gene Hackman had Alzheimer's, I had a sinking feeling about what had happened. He didn't know what to do after his wife passed away, he couldn't take care of himself. As far as we know, no one was routinely checking in with them to make sure they were okay or to drop by or send help if they weren't heard from.

Linda: It was a horrible situation!

Ann: It sure was! So, what actions can care partners take to prevent this from happening to them?

Paula: That brings us to our third topic: how to summon medical assistance. One easy way is for a care partner to wear a call-for-help pendant. All you need to do is press a button to get help for yourself or your person in an emergency.

Linda: You know, there was recently a post on an LBD Facebook group, about someone who used a pendant to call for help. It really saved the day in her situation.

Ann: That's fantastic! You know, if you're going to use a pendant, just make sure that you know what happens when you activate it.

Paula: Yeah, some of those alert pendants emit loud alarms or involve people calling out asking if you're okay.

Ann: Which could be extremely frightening to the person with LBD — and make matters worse — if they're already upset.

Linda: Exactly!

Paula: As an alternative to the pendants, consider using a feature or downloading an app on your cell phone, such as Medical Guardian or MobileHelp. Some smart watches and phones can be set up to send an alert if you fall. Some also have a quick emergency response mode you can use.

Ann: For example, on my iPhone I've set up Hey Siri. It's a voice-activated feature that enables me to command my phone to make calls or perform other tasks when I don't have my phone in hand — but it's still nearby.

Linda: I've got Hey Siri set up on my phone as well and it's been very helpful. But I think we still should have had someone checking in on us every day to make sure we were okay.

Paula: Well, you know, there are several apps that do that now too, for no charge. If you don't check in with the app, the app will message a designated contact person. You can add in more options for a fee, but this may be all that you need.

Linda: Wow! That might have been helpful in the Gene Hackman situation.

Ann: That tragic story highlights how important it is to have some kind of a plan in place.

Paula: It sure does. And, both you and your person living with LBD could also wear medical alert bracelets or carry medical alert cards. Some alert accessories allow you to load medical information, so emergency responders can quickly access everything they might need to know.

Linda: That sounds like a really great way to have information available.

Ann: Yeah, that recommendation was also included in the *New York TImes* article I mentioned earlier.

Linda: Interesting!

Paula: So, let's take a moment to summarize what we've talked about so far. We've discussed documenting important medical information and having it readily available.

Linda: And we've talked about creating an emergency plan, including the idea of setting up a notification tree and various ways to get help if something happens.

Ann: Now let's talk about what to do if an emergency happens and your person with LBD needs to go to the hospital.

Linda: Paula, when we were discussing the content for this episode one thing you'd mentioned was that the care partner should stay with them as much as possible to be their advocate.

Paula: Yes, your presence can also help your person stay calm.

Ann: So what do you do if the hospital staff tries to separate you?

Paula: If you're told you can't be with your person, make sure that hospital staff understand that your person has dementia, and may be unable to answer important questions or may become agitated. If they still insist on separating you, make sure they have your cell phone number and know where you'll be waiting.

Linda: Excellent point! The first time my husband was taken to the ER, we were fortunate that the medical team recognized the value of allowing me to stay with him. We spent hours waiting in a hallway before he could be moved into a room. I think my presence helped keep him calm, which benefited all involved.

Ann: Ugh, and we all know that those wait times and transitions in the ER can be so wearing and stressful for everyone.

Paula: Remember, not only do you need to be there to provide support and to advocate for them, but you also need to be present so you know what has occurred and can take notes. And this applies to trips to Urgent Care as well, and even to regular doctor appointments.

Linda: That really makes sense — even in routine appointments an extra set of eyes and ears are important. Especially with the fluctuating cognition that's so common with LBD. Even if your person is having a good day, they may not be able to get the complete story out when they're talking with the doctor or be able to remember a recommendation later on.

Paula: True, Linda. Now getting back to coping with hospital stays**,** sometimes people with dementia who are reacting poorly to being in the hospital are assigned "sitters" who stay with them around the clock to make sure they don't try to remove their IVs, or attempt to leave the hospital. These sitters can alert others if someone becomes overly agitated and can't be calmed down.

Linda: Hospital sitters? Wow, that's good to know!

Ann: So, how do you go about getting a sitter? Do you ask for one?

Paula: Depending on how your person is reacting to being in the hospital, the hospital may assign a sitter. But if they don't, you can request one if it looks like they're going to need constant observation. It's something to be aware of as a possible option.

Linda: If a sitter isn't provided, you could contact family members and friends to set up a watch schedule so your person isn't left alone.

Ann: In addition to stating that your person has dementia, staying close to advocate on their behalf, and requesting a sitter if needed, are there any other actions a care partner should take when their person is admitted to the hospital?

Paula: It's really important to make sure that the hospital staff know to check with you before giving any sort of antipsychotic medications.

Linda: Absolutely, and if you have an in-network hospital or one you've gone to in the past, you can have medical sensitivities listed on their medical record ahead of time.

Paula: My Dad's neurologist gave me a form that stated that he was allergic to the drugs that he had problems with, and to drugs that the neurologist did not want the hospital to even attempt using on my dad — drugs like Haldol. The neurologist said this was the best method to make sure that a drug wouldn't be given to him in the ER if my dad started having delirium or an emotional meltdown.

Ann: For more information about how tricky medications can be for people with LBD — because they can be really, really tricky — check out Episode 5 from our first season: Hallucinations and Delusions? Go with the Flow.

Linda: Yes, Ann, and medications were also discussed in our last episode: Season 2, Episode 1 — Safety First: How to Protect Yourself if LBD Behavior Becomes Violent.

Paula: We'll include a medication glossary provided by the Lewy Body Dementia Association and information about use of medications in emergency situations in the Resources section of our website for this episode.

Linda: That information can help you understand what the medication options are, if the hospital wants to introduce a new drug or needs to treat your person for hospital delirium.

Paula: Another thing that a person in my support group did to prepare for hospital visits was to have a written description of what her husband's baseline capabilities were, what he was normally able to do for himself.

Ann: Oh**,** that's a great idea because the hospital staff doesn't know what your person's capabilities are. I'm curious, Paula, what types of things did she include in her baseline list?

Paula: She included that he could normally feed himself, walk with the help of a walker, communicate what he liked to eat, and was able to handle a TV remote control. She also included his personal interests — for example, that he enjoyed listening to music.

Linda: I can see why having that type of information would be important.

Paula: Yeah, the hospital staff needs to know whether your person's current condition is normal for them or not. Otherwise, for example, they may assume that it isn't unusual for them to lie in bed all day without interacting with anyone, when normally they are very active and talkative.

Linda: And let's not forget that this might also be important information for you to document about yourself if there isn't anyone who can advocate on your behalf. That way the hospital staff knows what your baseline is and can better evaluate how you're doing.

Ann: That makes sense. And, Paula, do you have other suggestions to help inform hospital staff about your person so they receive appropriate care?

Paula: Yes, bring literature about LBD with you to share with people who will be caring for your person. The Lewy Body Dementia Association has pamphlets that can help others understand the uniqueness of this disease.

Linda: They do, and I found those pamphlets to be really helpful when my husband was in the hospital.

Paula: They also publish a free booklet for physicians called "Diagnosing and Managing Lewy Body Dementia — A Comprehensive Guide for Healthcare Professionals."

Ann: For simplicity, we'll include a link for ordering all these free materials from the LBD Association on our Resources page for this episode.

Paula: Another thing you can do to prepare for a hospital visit is to put together a to-go bag ahead of time with the personal items that you might need. This can make a trip to the ER, Urgent Care, or even waiting for a regular doctor's appointment go so much smoother.

Linda: And how about being sure to include a change of clothing for your person, especially if there are incontinence issues.

Paula: Many people in my support groups have expressed how beneficial having a change of clothing can be — and not only for your person but also for yourself. You can keep these clothes in your car so that you can easily access them if you need them in any situation.

Linda: Yes! I've found having an extra set of clothing helpful in non-emergency situations as well.

Paula: One time my dad had an accident in the Men's room while waiting for a regular doctor's appointment at the clinic.

Linda: Oh, my!

Paula: Yeah, my brother and I were with him, and my brother took my dad to the men's room. I had assumed he would help my dad out, but my brother just walked him to the door. It was fortunate that we were both there so I could wait with my dad while my brother ran out and got clothes for him. I felt so badly for my dad.

Ann: I'm sure you did. Paula, that brings up a good point, especially as we try to help the person with LBD retain as much dignity as possible. You as the primary care partner knew what kind of help your dad needed in the bathroom. Your brother didn't. It's the little things like that that you don't even think to communicate about that can really trip you up.

Paula: They sure can!

Linda: So in addition to clothing, what other items are good to have in a to-go bag?

Ann: I usually bring snacks and bottled water — and sometimes juice — so that I don't have to hunt around for vending machines or a water fountain. Plus, then I know I have fresh nutritious items on hand that we like and that meet our dietary restrictions and preferences.

Linda: Along with those necessities, you could include things that might make waiting less stressful.

Paula: Having a playlist of music on your phone, or on an iPad or tablet, along with some headphones, can help pass the time and keep your person relaxed.

Linda: Hmmm**,** that would have been very helpful while I was waiting with my husband in the hospital hallway between ER and room assignment. Other good distractions might be travel or wildlife videos, games or something your person can fidget with.

Ann: And If you don't happen to have your to-go bag with you when a medical emergency happens, ask a friend or family member to bring it to you.

Linda: Ah, that's a good idea, Ann**.**

Paula: I've found having these types of items to also be very helpful any time you have to wait for a while or when you are out of the house for a period of time.

Linda: You know, if you are going to urgent care or the emergency room, or even to the doctor's office, you may be able to find out ahead of time what the wait time will be because this can vary from clinic to clinic.

Paula: So make sure to have the phone numbers for your urgent care center and doctor's office handy. They should be listed along with other critical information on your medical history documents that we talked about earlier.

Ann: Keep in mind, your person may have been fine dealing with long wait times or a hospital stay in the past. But with LBD they may be much more impatient and susceptible to emotional mood swings or even what is called "hospital delirium."

Paula: Yes, there's something about being in the hospital that can trigger delirium. People can become irrational, angry, and really confused about what is happening around them.

Linda: As time goes by, you'll get a good sense of how your person reacts in different environments like hospitals and the doctor's office. You can take that into account during future trips.

Paula: Yeah, my dad had behaviors that only happened in the hospital! For instance, he'd vigorously rub his fingers on the edge of the sheets and would end up pulling the bedding apart. I figured out that this was a self-soothing technique he had developed. I found that if I brought along a small towel for him to handle, that was a big help, and his bed wouldn't have to get remade all the time.

Linda: Excellent! And talking about learning from experience, this seems like a good time to repeat something we've mentioned in other podcasts, which is the value of keeping notes about what's happening so you have a record of when things occurred, who was involved, and what the end result was.

Ann: Yes, great reminder Linda.

Paula: Yeah, you may think you'll remember these things, but there can be so much going on that you don't. Having things written down or recorded can really make a difference when you look back on a particular incident.

Linda: I certainly found that to be the case — especially when it came to identifying trends in my husband's behavior.

Ann: Hey Paula, speaking of hospital stays, when we were discussing the content for this episode, you'd mentioned that if someone ends up having a hospital stay and is on Medicare, it's critical for them to find out if their admission is under Part A or if it's considered Observation Status. Can you please take a moment and explain why this is important?

Paula: This is important because it affects what costs are covered. For example, if your person is admitted as an in-patient to a hospital under Medicare Part A, for a minimum of three days, and is then discharged to a transitional care unit or nursing home, that stay in transitional care is covered by Medicare.

Linda: But if they are only admitted for one or two days, it's not covered?

Paula: That is correct based on the current Medicare Part A rules. Now if they are coded as Observation Status, that is covered by Medicare Part B. In that case, if they need subsequent care, their stay won't be covered by Medicare!

Ann: Again, just to clarify, how a patient's admission is coded and how long they stay in the hospital will impact what type of subsequent care is covered.

Paula: Yes, that's true. If a hospital stay is considered observation status, a subsequent stay in a care facility for rehab is not covered.

Linda: And, I've heard that hospitals have been admitting more and more people under Observation Status — sometimes for several days — when the original intent of Observation Status was to determine whether or not the level of care that was needed required a hospital stay.

Ann: It's my understanding that Observation Status was also created to cover outpatient tests and procedures that need to take place at a hospital. It wasn't envisioned as something that would be in place for a hospital stay of multiple days!

Paula: That's correct, but that is how it is being used now. Unfortunately, this means that people are being discharged from the hospital and sent to a transitional care facility only to discover that their stay there isn't going to be covered by Medicare due to being under Observation Status at the hospital.

Ann: So it's important to ask what the admission status is as soon as possible. If you disagree with the status, talk with the doctor.

Linda: This is really good to know and it's also a good time to reiterate that we are not professionals giving out legal or medical advice here, we're talking about these things from the viewpoint of our own personal experiences. You should consult with the appropriate professionals for your situation.

Ann: Let's pause for a moment because we've covered a lot of things so far. This includes what caregivers can do to be prepared for medical emergencies and how to make the time spent in emergency waiting rooms and hospitals more successful. But there's one more topic we wanted to discuss in this episode.

Linda: There is**,** and that topic is completing the legal documents that are so important to have in place so you are able to make financial and healthcare decisions on behalf of your person.

Ann: We'll discuss two of the most commonly used legal documents in the United States: the Power of Attorney, which allows you to make financial decisions on someone's behalf, and the Medical Power of Attorney, or Health Care Agent, which allows you to make health care decisions for someone else.

Linda: We should mention, wherever you reside globally, check on your local policies and procedures to determine what is required in your area.

Paula: Designating a Health Care Agent is often part of creating a Health Care Directive, in which a person can state what sort of advanced care they wish to receive in situations where they can no longer speak for themselves. What this form is called differs from state to state; sometimes they are referred to as Living Wills.

Linda: Most people associate these forms, especially the Health Care Directive, or Living Will, with end-of-life decision making. But it's actually critical to get both of these forms done as soon as possible. They're needed in order for you to make medical, financial and housing decisions on your person's behalf.

Paula: This reminds me of a person in my support group who assumed he would be able to make decisions on his spouse's behalf because they were married. He found out this wasn't the case when his spouse was hospitalized due to a sudden crisis and she needed to move to memory care.

Linda: There were problems, I presume?

Paula: Yes. He was asked right away when they arrived at the memory care admissions office for a Power of Attorney form and a Health Care Directive. Without these forms, he wasn't able to make medication decisions, and even had a hard time finding out what medications were being given! He had to rely on the staff at the care residence to determine the appropriate level of care without his input and felt very much out of the loop.

Ann: I'm sure that was incredibly frustrating! So, what did he do? Was he able to get those documents?

Paula: No, his spouse was no longer competent enough to give permission to sign those documents. He was told he had to pursue guardianship or conservatorship, which involves going through the court system, not just a visit to an attorney!

Linda: Wow, so on top of dealing with the medical crisis and the upheaval due to Lewy Body Dementia, he had to deal with that issue as well!

Ann: You would assume that being married would give you the ability to speak for someone else in these situations, and it's shocking that isn't always the case.

Paula: That's why it is so important to have these documents done before there's a crisis and while you — and your person with LBD — are still legally competent to sign these forms.

Linda: Looking back at our situation, we did have all three documents you mentioned, Paula — a POA, a medical POA and on the recommendation of our attorney, I also went to court to obtain legal guardianship. Several of my friends said that guardianship wasn't necessary but I followed my attorney's advice and having guardianship in our case proved to be extremely helpful.

Ann: Oh, that's very interesting, Linda. Don't rely on hearsay. It's an absolute must to consult with a legal professional for advice about your specific situation. It's money well spent.

Paula: There are also family assistance organizations that can help you navigate this process.

Ann: And organizations that offer free or low-cost legal consultations.

Paula: We'll list some of these organizations on our Resources page for this episode.

Linda: And keep in mind, you need those documents not only for your person but also for yourself, so someone else can speak on your behalf in case you aren't able to make your wishes known.

Paula: Typically, the first document that people get done is a Power of Attorney, which is referred to as a POA. A POA enables you to make financial decisions for someone if they are no longer able to do so. My parents did this after my father retired. They named each other as their Power of Attorney and named me and my sister as successor Power of Attorneys. That way if anything happened to either of them, my sister or I could step in to help out.

Linda: So the Power of Attorney will give you the ability to pay bills, sell property, and handle decisions about various assets, right?

Paula: Yes.

Ann: Keep in mind though, that some places — especially investment companies — may also require their own forms to be completed.

Paula: I experienced that when I had to take over my Dad's finances. When I went to the two banks where he had his accounts and investments, I had to complete their forms. But, if I remember correctly, I still needed that regular Power of Attorney form in order to do those additional forms!

Ann: So check with your financial institutions to find out what documents they require you to complete. If possible, become a co-owner on accounts.

Paula: And remember, a Power of Attorney document is only effective during that person's lifetime.

Linda: So, Paula, the POA only covers financial decisions, right? You need a different type of document in order to make health care decisions.

Paula: Correct, for that you need what is sometimes called a Medical Power of Attorney. This is usually part of a Medical Care Directive, which enables a person to define the type of care they would want in situations where they wouldn't be able to make their wishes known. As part of that process, you name someone to be your Health Care Agent who can speak for you.

Linda: Now, you can be as specific or as general about your health care preferences as you want to be when completing this document. You can state whether you would want invasive types of treatment, like tube feeding or artificial respiration, or if you would rather not go that route.

Paula: Yes**,** and being someone's Health Care Agent will give you the ability to have a say and to get information about that person's medical treatment.

Linda: Absolutely, and again, like I said previously, don't forget about yourself in all this! If something happens to you, who would you want to speak for you? For example, if you've completed a Health Care Directive in the past and had named your spouse as your health care agent — and now your spouse has LBD — you'd want to have your

Health Care Directive updated because your spouse would no longer be able to carry out that role.

Ann: Also consider who could step in and make decisions on behalf of your person if you aren't able to do so.

Paula: Now be aware that if you are in the US, these documents are different from state to state. If you reside in one state, and you've found that the best care residence or hospital for your person is across the border in another state, you may need documents prepared in both states.

Ann: That's a good reminder, Paula. And remember, if you don't already have an attorney or aren't sure where to turn, family assistance non-profit organizations that specialize in helping seniors and caregivers can help you get the ball rolling.

Linda: The social workers at the hospital or care residences can also help — they would be aware of local resources.

Paula: We do list information about how to locate these types of organizations on our Resources page for this episode. These same organizations help with caregiver coaching and counseling as well. You might end up at an attorney's office but some documents may just need to be notarized or signed by witnesses. Again, it differs from state to state, as do the rules governing what is needed to make different financial or health care actions. So it's important to get legal advice that applies to your situation and location.

Linda: We encourage you to get your Power of Attorney and Health Care Agent forms done. Having these documents in place can really help you deal with the challenges you'll be facing in the future.

Ann: I have a question for you, Paula. How much attention do you think emergency medical professionals really pay to health care directives that spell out what type of treatment you'd prefer in a crisis?

Paula: Well a health care directive provides a guideline about your preferences. If you want more control about what happens to you in a life-threatening emergency, consider having a POLST — which is a Physician/Provider Orders for Life-Sustaining Treatment. This document has the weight of being "doctor's orders" and is often done when someone is facing a terminal illness that might incapacitate them to the point where they can't speak for themselves.

Linda: Yes! One very helpful nurse advised me about the POLST and it became a critical game changer in our journey.

Ann: So, just to clarify, a health care directive is something you create stating your wishes and a POLST is authorized by a person's physician?

Paula/Linda: Correct.

Linda: Once you have the legal documents you need for your situation, make sure they're readily available.

Ann: And that you distribute them when and where they're needed.

Paula: I kept copies of my dad's Power of Attorney on hand so that I could send it to the financial institutions I was dealing with on my dad's behalf. My sister, who was his Medical Power of Attorney, or health care agent, made sure that document was on file with my dad's doctors and at the care residence and at his hospital.

Linda: I had a situation where the nurse on duty at my husband's facility had him transferred to a hospital but did not send the POLST with him. The hospital was going to administer a feeding tube, which was against my husband's wishes. I had to take action quickly to get the POLST to the hospital.

Ann: That just shows how important it is to have these documents available and to have them in the hands of the people who need them.

Paula: Your attorney or whoever is helping you navigate this process, can give you guidance on how to use these forms and who to give them to.

Linda: This seems like a good time to wrap up this episode. We started by talking about creating medical information and medical history documents and putting together an emergency contact list.

Ann: And then we discussed how to summon emergency assistance and the things you can do to make ER and hospital visits more successful.

Paula: And last but not least, we talked about making sure that you have the legal documents you need in place for your situation.

Ann: I just want to remind our listeners that we have transcripts of our episodes on our website LewyBodyLife.com in case you'd like to read through them or print them and highlight the parts you find most valuable.

Linda: Good idea, I think we can summarize the theme of this episode by saying that there are a lot of things that you *can't* plan for with LBD. So, plan for what you can!

Ann: And Paula before we go, let's talk about our next episode.

Paula: In our next episode, we'll talk about "showtiming" — the ability of someone with LBD to rise to the occasion and act very normal especially in social situations. This can be a blessing but can also pose some real problems.

Ann: Yes, family and friends can have a hard time accepting the reality of what you're experiencing — regardless of whether there's a diagnosis — when your person appears high functioning during social visits, while out with others, or even during medical appointments.

Linda: We'll also talk about ways that being an LBD caregiver affects your relationships with friends and family, how to let people know about the diagnosis, and how to discuss the issues you and the person living with LBD are experiencing.

Paula: So, please tune in to our next episode "When Outsiders Think You're the Problem: It's Showtime."

Linda: Oh, and before we go, 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. I'd especially like to thank Kyung Endres! Kyung helped spread the word about this podcast via the Minnesota Healthy Brain Initiative Newsletter.

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

Ann: For more information on the topics covered in this episode, please visit our website at LewyBodyLife.com and check out the resources listed there. Thanks for listening and don't hesitate to use our Contact Us form if you have questions or a topic you'd like to recommend!

Paula: We wish you strength and courage as you travel the LBD journey.

END