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BEHAVIORAL CHANGES IN LEWY BODY DEMENTIA Care Brief #4 – Non-drug Strategies to Manage Behavioral Changes

Sometimes, despite the best efforts to prevent the behavioral symptoms of dementia, one or more of these symptoms occur: psychosis (hallucinations; illusions; delusions, including paranoia, misidentification, Capgras syndrome, and reduplicative paramnesia; disinhibition; wandering; catastrophic reactions; and verbal and physical agitation) and mood or affective changes (depression, apathy, anxiety). *(Learn about the definitions, causes, and non-drug strategies that may help prevent behavioral symptoms in Care Briefs #1-3.)*

This Care Brief summarizes strategies that care partners can use to manage, reduce, or perhaps even eliminate many behavioral changes. In fact, the approaches with the strongest research support are those provided by family care partners. Discussed in this brief are non-drug strategies care partners can implement. Because each person living with LBD and each care partner is unique, it may take several attempts to find the best strategies for a given situation or time.

Use a problem-solving approach to identify the behavior, determine its cause, and select a strategy. Answer questions such as

- What is the behavior? What might be causing it? Is there a medical issue? Did something or someone trigger it?
- Is it disturbing to the person with LBD? Some behaviors do not cause the person living with LBD stress, so no intervention is needed – even if they are disturbing to the care partner.
- Does it pose a threat to the physical safety of the person or anyone else? If so, remain calm and consult a health care professional.
- What are some possible strategies? Which one or two seem most likely to be successful?
- Take into account the person's feelings, and make sure the person living with LBD feels heard.
- After trying a strategy, was it successful? Does it need to be modified or replaced?

Keep a record of what happened, when, and for how long: identify causes or triggers, non-drug and drug strategies and therapies tried with what results. Share this information with the person's doctor.

Continue using the non-drug strategies aimed at preventing behavioral changes (Care Brief #3): closely monitor the person's physical health; create a safe and comfortable home environment; establish and maintain a daily routine; make sure the person gets enough sleep; provide sufficient healthy and attractive food; be sure that the person stays hydrated; make bathing a calm and safe activity; avoid media with potentially disturbing content; communicate positively in a calm reassuring voice; engage the person in enjoyable meaningful activities; and identify people who trigger behavioral changes.

Continue to incorporate one or more of the non-drug therapies discussed in Care Brief #5: physical, occupational, speech, art, music, aroma, reminiscence, touch, massage, pet, nutrition, light, validation, support group, individual, and family therapies.

Don't take any behavior personally. Remember that it is the disease that is the problem, and the person with LBD is not saying and doing things intentionally to hurt, frustrate, or annoy the care partner. The challenging behaviors are the person's response to what is happening in their environment or within

themselves. They are a way for the person to communicate needs and concerns. Focus on the underlying emotion (fear, worry, frustration?) rather than what is actually said or done. This allows you to respond more effectively by addressing the issue that is triggering the underlying emotion.

Stay calm and carry on! Speak in a calm voice with reassuring words, composed facial expressions, and relaxed body language. Your attitude can calm the agitated person.

Don't argue or try to reason with someone living with LBD. Their cognitive functioning is in decline, and they may not be able to think logically and rationally, so they become frustrated or agitated. Instead, it's okay to agree with benign inaccuracies (ask yourself, does it matter?), apologize even if you did nothing wrong, agree to solve the problem ("I'll call the bank tomorrow"), provide a response that makes sense to the person ("they already ate, they should be leaving soon"), or side with them ("I know, it's annoying that they haven't left yet!").

Agree with and validate what the person is feeling and saying. Acknowledge their feelings and offer reassurance. "I can see that you're upset. Let me help you." If the person wants to go home (even when they are home), say things such as "What do you want to do at home?" Talk about some aspect of the home that can redirect the conversation. Often, when you join in the discussion with questions or comments, you can redirect the person.

Redirect and distract the person with an activity they enjoy. First, validate the emotion that you think is underlying the behavior, and then redirect. Perhaps offer them a favorite snack or a beverage. Engage them in a TV show, music, or hands-on activity. Redirect the conversation to a topic the person enjoys. For example, say something like, "I know you are worried, but we are in this together". Then redirect by carrying out an activity, "Let's go run a few errands, I like it when you come with me".

Use "therapeutic fibbing" to enter into the person's reality rather than trying to correct them. Most people do not want to lie, but complete honesty is not always the best policy with a person who can't process information logically and becomes confused, anxious, fearful, and angry. To keep the person from being distressed, say things to calm them. For example, if a person is worried that the neighbors are digging holes in the backyard, it may help to say "I will go talk to them" even if that is not the case.

Sometimes, leaving the room and returning later helps. Be sure that the person is safe, then leave the room. If the person thinks a spouse is a duplicate or an imposter, go along with it and ask questions about the "other" spouse. Leave the room for a few minutes, and return while announcing "I hear you were looking for me". The care partner might leave the room on the pretense of taking care of something that is disturbing the person living with LBD and return to say that the task is done ("I just finished spraying for the bugs that were in the family room, and they are gone."). Return with a favorite drink or snack.

Use physical contact to calm the person if the person is willing to accept it. Pat their arm or back; hold their hand; massage their hands, shoulder, or temples; or give a hug to reassure them.

Only use strategies that maintain the individual's personhood with dignity and respect. For example, do not use condescending speech or baby talk, or talk about them as if they aren't there. Show acceptance and give them reasons to feel worthy. Include them in discussions, use their names or terms you have always used, and respect their privacy.

See Behavioral Changes in Lewy Body Dementia. Care Brief #7 for additional resources on this topic.

The information set forth in this material is intended for general informational use only. It is not intended to be medical, legal, or financial advice or to take the place of competent medical, legal, or financial professionals who are familiar with a particular person's situation. Each individual is advised to make an independent judgement regarding the content and use of this information.