

BEHAVIORAL CHANGES IN LEWY BODY DEMENTIA

Care Brief #3 – Non-drug Strategies that may Prevent Behavioral Changes

Most people living with LBD will experience one or more of the following: behavior changes: 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). *The definitions, descriptions, examples, and causes of these behaviors are discussed in Care Briefs #1 and 2. This Care Brief summarizes evidence-based, non-drug strategies into daily life that may possibly prevent or curb behavioral changes.*

Closely monitor the person's physical health for medical conditions that may trigger behavioral changes, including hallucinations or delusions. Take measures to avoid, identify, and remedy any infections (especially urinary and respiratory tract infections), constipation, hearing or vision problems, too high or too low blood pressure or blood sugar levels, pain from any cause, dehydration, the side effects of drugs, and the interactions of two or more medications. Schedule visits with the person's primary care physician, LBD specialist, and/or other specialists on a regular basis.

Create a safe and comfortable home environment that addresses the physical and emotional needs of the person living with LBD, maintains quality of life, and supports continued functioning. Such an environment allows the person as much mobility and ability to perform activities of daily living as possible. Consider bathroom features (add grab bars, risers on the toilets, and benches in the shower), mobility enhancements (install ramps, widen doorways), and safety elements (reduce clutter, remove throw rugs, add lighting). Arrange the home in a way that encourages the person to remain involved in activities and with others, but also provide an opportunity for time for one-on-one interactions and quiet time.

Establish and maintain a daily routine that is consistent and unrushed, but allows for some flexibility based on the current needs and wishes of the person. Sequence activities in a way that matches the person's changes during the day. Determine the best times for getting up, bathing, eating meals and snacks, taking medications, going to the bathroom, physical activity, napping, engaging in solo activities, participating in activities with others, and going to bed. Maintaining daily rituals and habits are a source of comfort, and provide a person with a sense of personal control since they are aware of what is going to happen. It may help to post a concise outline of the daily schedule.

Make sure the person gets enough sleep by reinforcing the normal sleep-wake cycle and providing a supportive sleep environment. Establish regular times to go to bed and wake up, use the bedroom primarily for sleeping, have some type of regular calming activity at bedtime, and avoid stimulating food and beverages (caffeine, alcohol, sugar). Limit fluids for a few hours before bedtime, use the bathroom directly before bed, and minimize the amount of light and sound. How much the person naps depends on whether they appear refreshed after their daytime naps and whether napping interferes with nighttime sleep. If snoring is an issue, it may help to raise their head with a pillow or bed control. If a person living with LBD acts out dreams, their bed partner needs to stay safe (use pillows as barriers or sleep in another room). Consider seeking treatment from a doctor familiar with REM sleep behavior disorder (RBD).

Provide sufficient healthy and attractive food to maintain a desirable weight and to keep the person involved with mealtime rituals. People living with LBD are at risk for weight loss and malnutrition. They may have motor issues (slowness, stiffness, tremor) or diminished appetite, mood disorders, trouble swallowing certain foods, cognitive difficulties (trouble with sequencing or organizing oneself), or apathy.

Serve meals that meet nutritional requirements, satisfy any special needs (e.g., low sugar, low salt, gluten-free, and modified consistency), are visually appealing, and taste good. If the person has difficulty feeding themselves, provide adaptive utensils, assist with feeding, allow sufficient time, and don't call attention to their problem. If the person is a poor eater, try nutrient-rich foods like homemade smoothies. Provide enough snacks to maintain blood sugar and energy levels throughout the day.

Be sure that the person stays hydrated because dehydration is a trigger for behavioral and mood changes. Have a variety of beverages, plain water or non-caloric, sodium-free flavored water readily available throughout the day – at all meals and between meals. Decaffeinated coffee and herbal teas add variety. Avoid too much juice or sugary drinks – especially if the person is diabetic. Remember that many foods, particularly fruits and vegetables, have significant water content, so include them in meals and snacks. If needed, provide adaptive utensils (cups with handles or spouts, straws).

Make bathing and other hygiene activities pleasant, safe, and calm. Establish a routine, prepare all items beforehand, talk the person through each step in a calm voice, maintain modesty as the person desires, regulate the room and water temperature, allow the person to do as much as possible for themselves, provide choices, and include spa-like elements (music, aromatherapy, special body wash and lotion, soft towels). Ensure dental health because dental problems may cause behavioral changes.

Avoid media with potentially disturbing content. Many television programs, movies, songs, websites, magazines, and newspapers contain violent, overly sexual, frightening, and other content that may trigger hallucinations, delusions, paranoia, and agitation. Some people living with LBD may find it hard to distinguish what is happening in the media from what is really happening.

Communicate positively in a calm reassuring voice. Use simple, clear language. Explain what is happening, step by step. Speak at eye level with a speed that is neither too fast nor too slow, and at the level the person can hear. Communicate where there are no distractions such as the TV or other people talking. Reinforce what you say with positive body language, facial expressions, and gestures. Try to understand the perspective of the person living with LBD, listen to the feelings behind what the person is saying or doing and stay calm. Validate the person's feelings and apologize ("I know this is really frustrating, I'm sorry"). Don't argue, point out mistakes, reality orient, yell, or provide lengthy explanations.

Engage the person in enjoyable meaningful activities, but have realistic expectations. Allow the person to make decisions between two choices. Interact one-on-one and/or involve other people to provide social support. Encourage participation in household tasks (folding clothes, drying dishes, or dusting), exercise, and a variety of activities (coloring books, electronic games, and activities to keep their hands busy - a soft toy, doll, worry beads, or a box containing interesting objects).

Identify people who cause stress and trigger behavioral changes. Educate those individuals on how to interact more effectively. Consider changing home helpers or members of their health care team, if needed.

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.

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

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