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BEHAVIORAL CHANGES IN LEWY BODY DEMENTIA

Care Brief #1 – Introduction and Overview

While most people living with LBD experience behavioral or mood changes, the changes vary from person to person, and they may occur at different times as the disease progresses. Some types are more common than others, and some are benign while others are more intrusive and distressing. Behavioral changes contribute significantly to caregiver burden. Fortunately, there are ways to address these behavioral changes - with and without drugs. **This care brief provides definitions, descriptions, and examples of common behavioral and mood changes.** Other briefs in this series discuss causes/triggers (#2), non-drug treatments and therapies that may be helpful in preventing and managing behavioral changes (#3-5), drug treatments (#6), and additional resources for care partners (#7).

Visual hallucinations are when the person sees a fully formed image that isn't there. Up to 80% of people living with LBD experience visual hallucinations that can be very detailed involving animals, people, children, or other living or inanimate objects. They often interact with their hallucinations - for example, talking to the small children they see. Hallucinations may be pleasant, or they may be disturbing causing the person to act out verbally or physically. Often hallucinations are more disturbing to loved ones than they are to the person experiencing them.

Auditory hallucinations are false perceptions of sound such as buzzing, knocking, background music, or people speaking. They may occur along with a visual hallucination.

Feelings of presence are vivid fleeting sensations, typically lasting only a few seconds, that someone else is present, perhaps off to the side or behind, but not visible.

Illusions are visual misperceptions. Things are wrongly perceived or interpreted by the senses. For example, a coat rack may look like a person, a carpet pattern may look like snakes, or a tree branch outside the window might look like a potential intruder.

Delusions are false beliefs which the person believes are real but which have no evidence or basis in fact. It is common for people living with LBD to believe that others are stealing things; their house is not their home; their spouse or other loved one is an imposter; they have been abandoned; or their spouse has been unfaithful. Not all delusions involve suspicions; a person might believe that they are still employed or that deceased loved ones are still alive. The following are some common types of delusions.

- **Paranoia** is a type of delusion in which the person believes they are being harmed or persecuted. The person has an irrational distrust of others and becomes suspicious, fearful, or jealous. A variant of paranoia is delusional jealousy, typically thinking that a partner has been unfaithful. Paranoia is a risk factor for aggressive behaviors.
- **Misidentification** is based on misperceptions of what is seen or heard. People may not recognize themselves in a mirror, they may misidentify others, or they may believe what they view on TV or other media is occurring in real-time in their location.
- **Capgras syndrome** is a delusional belief that a person - often a spouse, other close relative, or a friend - has been replaced by an identical double or imposter.
- **Reduplicative paramnesia** is the delusion that there are two or more identical people, places, or things. A person may think that their spouse is two or more people (perhaps sisters or women with

- different roles), some of whom are “good” while others are “bad.” They may also believe that there are replicas of their home, down to every detail.

Depression is a mood disorder that affects people differently. They may feel sad, hopeless, discouraged, tearful, or irritable for extended periods of time. They may withdraw socially; have loss of appetite; sleep poorly; feel fatigued; or express feelings of worthlessness or guilt. At the extreme, they may think or talk about death or suicide – perhaps, attempting it.

Apathy is a lack of interest in things that were typically important to the person. There may be less motivation for normal activities and personal care. They may show little initiative or be unresponsive emotionally. A person with apathy alone will not have the symptoms of depression; instead, they feel as if they have lost their energy or spark.

Anxiety is a normal feeling when it does not occur often or for long periods of time. When it is persistent and intense, anxiety interferes with everyday life. People living with LBD may have generalized anxiety, panic disorders, or phobias. They may feel very worried, tired, or irritable. They may develop fears of the dark, being left alone, crowds, or bathing. Some will feel anxious most of the time; others will have sudden, intense attacks of anxiety.

Agitation includes inappropriate verbal and physical behaviors which can be non-aggressive or aggressive toward self or others. Most agitated behaviors are the result of discomfort or discontent. Common forms of agitated behavior in LBD are:

- *Physically non-aggressive behaviors*: emotional or physical restlessness, repetitive mannerisms, pacing, trying to get to a different place, handling things inappropriately, hiding things, inappropriate dressing or undressing.
- *Verbally non-aggressive behaviors*: negativism, expressing dislike for everything, continual requests for attention, bossiness, complaining, interruptions, repetitive words or sentences.
- *Physically aggressive behaviors*: hitting, pushing, scratching, grabbing, kicking, and biting.
- *Verbally aggressive behaviors*: screaming, threatening, cursing, temper outbursts, and making strange noises.

Disinhibition is when a person behaves impulsively and inappropriately. They may exhibit poor insight and judgment. The disinhibition may lead to aggressive behavior, self-destructive actions, or sexually inappropriate speech and behavior.

Wandering takes several forms: wandering off from others, leaving the house unaccompanied, walking aimlessly, night-time wandering, following another person, or repeatedly checking on the location of a spouse or caregiver.

Catastrophic reactions are extreme and sudden emotional reactions that are expressed with physical and/or verbal outbursts that seem inappropriate or out of proportion to the situation. The response may be triggered by something happening at that time or an event from the distant past. These reactions can be a result of frustration, cognitive overload, or the inability to communicate needs or perform tasks.

See *Behavioral Changes in Lewy Body Dementia - Care Brief #7* for additional resources on these topics.

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.