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BEHAVIORAL CHANGES IN LEWY BODY DEMENTIA Care Brief #2 – Causes of Behavioral Changes in LBD

Many individuals living with LBD experience behavioral changes that can be distressing to the person experiencing them as well as to loved ones. These include: 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). (See Care Brief #1 – Introduction and Overview for definitions, descriptions, and examples of these behavioral and mood changes.)

This Care Brief summarizes possible causes or triggers for behavioral changes, to help LBD families understand, prevent or minimize the symptoms, develop strategies to cope with them, and support the person with LBD and their care partners. Some behaviors are a direct result of the changes in the brain from the disease itself, but not uncommonly, physical or health issues, environmental influences, as well as types of social interaction and communication may also produce or intensify problems.

One way to view behavioral and mood changes is to consider them *responsive behaviors*. The 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. The care partner's job is to be a detective and examine events that led up to the behavior and the events that made it worse or better. This allows the care partner to recognize that the person is not the problem; the person has a problem.

Changes in the Brain – The main culprit for LBD symptoms is the disease itself. The location and number of Lewy bodies play a role in behavioral and mood changes. The build-up of the alpha-synuclein protein causes the neurons to be less effective and they eventually die. The Lewy bodies also affect brain chemicals – neurotransmitters - that activate different brain functions. Depending on where the damage occurs, there is a decline in the functions associated with those regions (memory, cognition, movement, emotions, etc.). These and other changes in the brain may result in hallucinations, illusions, delusions, paranoia, misidentification, Capgras syndrome, reduplicative paramnesia, depression, apathy, and anxiety.

Health issues - A variety of health issues may cause or trigger many of the behavioral changes. It is important to identify if one or more of the following might be an underlying cause.

- Extreme tiredness, fatigue
- Changes of sleep patterns or sleep-wake cycle (Circadian rhythm) resulting in sleep deprivation
- Physical discomfort: pain (arthritis, dental, headache, etc.), fever, constipation, too hot or too cold, hunger, thirst, wet from urinary incontinence
- Fever, infections (especially urinary tract infections – UTIs) and other illnesses
- Loss of autonomic functioning such as incontinence and swallowing problems
- Parkinsonism - movement problems that interfere with the person's ability to perform activities of daily living (ADL's) – stiffness, slowness, balance and gait problems, falls
- Problems with vision or hearing
- Medication side effects (new medication, dose of medication, new side effects of a medication used for years, or interactions between medications, anesthesia)

Environmental Factors – Behavioral changes may be triggered or worsened by the physical environment or by task demands. Here are some possible triggers.

- Lighting is too dim which may trigger misperceptions or visual hallucination

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- Noise, too loud voices and other sounds, unpleasant sounds, persistent or sudden sounds
- Competing sounds (TV in background, several ongoing conversations)
- Temperature too hot or too cold
- Unsafe environment (actual or perceived) that threatens the need to feel safe and secure
- Not enough visual contrast which may make it hard to find the toilet or other places
- Objects that can be misinterpreted (mirrors, drapes, coat stands, art work, etc.)
- Too much clutter may trigger misperceptions or visual hallucinations
- Spaces that are difficult or unsafe to navigate
- A sudden change in environment (including a visit to the ER, hospitalization, transfer to a rehabilitation facility, a vacation, or move to a new home or long term care facility)
- Uncomfortable clothing
- Over-stimulation or under-stimulation
- Too few meaningful activities to occupy time leads to boredom
- Expectation of what the person living with LBD can do is too high which leads to frustration
- Expectation of what the person living with LBD can do is too low which leads to unease, dissatisfaction, or apathy
- A traumatic or distressing incident
- Too many people in the immediate area
- Social isolation and lack of social support
- Rough, abrupt, insensitive physical handling

Social interaction and Communication: Challenging behavior may be triggered by how care partners and others interact and communicate with people living with LBD.

- **Inability to understand** – Others may speak too quickly, provide too many details, point out mistakes, argue, quiz too much, or correct too much. This may trigger feelings of frustration and provoke feelings of sadness, anxiety, anger, or agitation.
- **Sense of loss** – When the person is unable to do many activities of daily living and needs assistance, the loss of independence and privacy may evoke intense emotions including feeling vulnerable, afraid, offended, or agitated. The person may feel a sense of loss giving up driving or needing help with personal hygiene tasks such as bathing and toileting.
- **Fear** – The world can feel quite overwhelming and terrifying to a person living with LBD. They yearn for and seek places, people, and times that were less frightening.
- **Need for Attention** – Often a person living with LBD expresses a need for attention by exhibiting agitation and aggression. They are not able to figure out how to tell someone they have an unmet need. Perhaps they are in pain, feel ill, or are bored, angry, or sad. They may also have a need to be comforted by someone familiar.
- **Reaction to Negativity** – People living with LBD are still tuned in to others around them. They may sense negativity in others and react with anxiety, agitation, and/or aggression.
- **Grief** – Although a person living with LBD may not be able to describe what they feel, they are aware of losses that cause grief. It may be the loss of a friend, family member, pet, or activities and relationships that they previously enjoyed.
- **Responses to hallucinations and delusions** - When a person believes something is real, they want to be heard and taken seriously. If the person's feelings are not validated, anxiety, agitation, aggression, wandering, or disinhibitions may escalate.

See Behavioral Changes in LBD - Care Brief #7 for additional resources on this topic.

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