

DEMENTIA WITH LEWY BODIES (DLB)

CAREGIVING CHALLENGES

Some of the challenging caregiving issues with patient with Dementia with Lewy Bodies are: cognitive decline, memory loss, visual/spatial problems and Parkinsonism. Another challenge is the daily fluctuation in cognition happening throughout the day. Some patients with Lewy-Body Dementia have well formed hallucinations and sometimes delusions. The hallucinations are usually not threatening to the patient.

The lack of memory for events or people can make the individual extremely anxious about daily life. This can be exhibited with asking questions, repeating information, preparing for appointments/day care well ahead of time, and use of notes and reminders. Tasks that used to seem routine become overwhelming, which can cause apathy or a lack of initiative. For example, the person who has always enjoyed puzzles no longer likes puzzles because they are too overwhelming and require skills he/she no longer possess. Visual/spatial problems are particularly noticeable, and he/she is often unable to even copy simple figures. Finally, agitation can occur often as people become less able to interpret the environment and control or express their feelings. This can be seen in people with dementia who may strike out when others are caring for them. These behaviors are very difficult for caregivers, who are trying to provide care and understand the changes in their loved one.

STRATEGIES FOR COPING

As with all dementia, the major strategy is to keep the goal in mind. Many caregivers are trying to make everything perfect and they get very upset, stressed out and frustrated when the patient does not cooperate as they plan. Therefore, try to use the good days and enjoy the time with your loved one and continue to socialize, travel, be physically active and participate in activities that are enjoyable to both of you. The lack of memory for events or people can make the individual extremely anxious about daily life. In more advanced stages, the patient may not be able to recognize caregivers and family members. That can be very distressing for both parties involved. Often, familiar activities that may be well memorized will continue to be enjoyable for the person with DLB and should be encouraged. However, trying to learn new tasks or starting new hobbies may be frustrating or overwhelming.

Anticipate misinterpretation by the individual with dementia. They are often no longer able to accurately interpret verbal or non-verbal cues which can result in anxiety and frustration in both the individual and the caregiver. Try to be clear and concise in your communications, repeating things as needed using the same words or message. Reduce extraneous noise and distractions when trying to communicate. Do not use confusing pronouns (he, she, it) but rather names and specific titles. Try to imagine what someone MIGHT think you are trying to do or say if they were unable to think clearly.

Remember that all behavior has a purpose. Many experts believe that some of the behavioral symptoms that people with dementia exhibit such as shouting out or striking out are meaningful. Although the person does not generally intend to disrupt things or to hurt someone, they do intend to be noticed and perhaps communicate a need that is not being met. In addition, it is important to remember that while these behaviors are meaningful, they are not intentional and the individual is not doing this “on purpose” but more likely in an attempt to convey a message that they can longer explain in words. Slowing down, trying to see the world thru their eyes and trying to respond to the

“feeling” behind the behavior rather than the behavior itself, may allow you to prevent an emotional crisis.

Since memories from the distant past are not usually affected, reminisce about the past and encourage discussions about people and places that are familiar and evoke pleasant feelings for both of you. Watching family videos, looking at photographs or reviewing travels from the past can allow the person with DLB and the caregiver to continue to share experiences and feelings. Allow the person to share the history they remember with family members, grandchildren and friends. It can be fun for all involved and so satisfying for the person with dementia to continue to feel connected and to contribute.

Be flexible. The disease is progressive. The symptoms and needs will change over time. If strategies such as notes or reminders, are no longer working, don't use them! A successful intervention at one stage, can be a frustration and disaster at another. Seek help, ask for advice, learn from others who have had similar experiences. More challenging behavioral symptoms such as resisting care or being aggressive can be particularly difficult and often require a very individualized approach. Talk to your doctor about approaches, both pharmacological and non-pharmacological.

SAFETY

People with DLB have an increased risk of falling, because of the parkinsonian symptoms, rigidity, small steps and bradykinesia (slow moving). Installing safety bars in bathroom and bathtub/shower can help with personal care. Some patients are helped by a walker. They may need a reminder to use the walker. In some cases a wheelchair is necessary, especially for going out of the house. Good footwear is essential. Some DLB patients experience vivid hallucinations but are usually not especially bothered by them, but it may confuse them at the moment. Do not argue with the patient about the hallucinations. Some patients may develop swallowing problems – monitor their intake, especially the liquids, and if they persist talk to the doctor (a swallowing evaluation may be necessary).

One of the priorities for caregivers is the safety of their loved one with dementia. As dementia progresses, the memory and judgment of the individual becomes impaired and he/she is often no longer able to anticipate or avoid dangerous situations. This can be an overwhelming responsibility for a caregiver and require some creative strategies for coping.

Supervision

In the early stages, concerns about supervision may be minimal as the person with dementia is still able to make appropriate judgments about safety. However, the need for supervision usually increases as he/she becomes more forgetful and their judgment becomes poorer. It is important at this stage to try to provide the appropriate level of supervision. This is often difficult to determine and involves evaluating the risk of the behavior actually or potentially occurring, the consequences, should it occur, and the ease/discomfort involved in protecting the person with dementia. Supervision can include simple reminder phone calls for medications, alarms on doors to prevent exiting, and actual personal supervision to prevent physical injury or harm. Some areas to review when considering level of supervision include the ability to handle emergencies when left unsupervised, ability to use appliances safely, and ability to safely answer the phone or door when left alone. Wandering often occurs in later stages when people may

be confused about where they are or are trying to find a familiar person or place. If there is a concern about this, enrolling in the Safe Return program should be considered. This program, which is administered by the Alzheimer's Association, provides national registration and identification of people with dementia to assist in locating them should they wander away or become lost.

For more detailed information:

[Alzheimer's Association Safe Return](#)

Alzheimer's Association

ENVIRONMENT

Providing increasing supervision is a difficult and time-consuming task for many caregivers. If possible, modifying the environment to limit exposure to potentially dangerous situations can allow patients to continue to be independent and safe. Especially in the early stages, reminders and cues in the environment may be enough to keep the individual safe, for example, posting the steps involved in a task or labeling where things are kept. Later, strategies which limit the exposure to potentially dangerous situations may be considered. When using the stove is anticipated to be a problem, removing stove handles is a good solution. You may also choose to use childproof handles on cupboards with dangerous materials in them. When more supervision is needed, it is best to assess each situation individually. Gradually increase the amount of supervision needed to maintain as much independence and autonomy as possible in as safe a setting as can be provided.

Visit our **[Resources for Dementia with Lewy Bodies](#)** section.