

INTRODUCTION

LBD is a complex disease that can present with a range of physical, cognitive, and behavioral symptoms. Many caregivers find that behavioral symptoms (e.g., hallucinations, delusions, aggression, agitation, apathy, depression and anxiety) are the most distressing and difficult-to-treat aspects of LBD. This paper discusses some of the causes of behavioral symptoms, as well as strategies and treatments to reduce their frequency and severity.

UNDERSTANDING BEHAVIORAL SYMPTOMS

Some behavioral symptoms of LBD are subtle and may go overlooked for some period of time. Other symptoms are easily recognizable the first time they occur. Here are some examples of the kinds of behavioral symptoms seen in LBD:

Behavioral Symptom	Definition	Examples
Hallucinations	Perception of an object or event when the object or event is not really present. Typically visual in LBD, but rarely, hallucinations can be auditory (hearing), olfactory (smell), gustatory (taste), or tactile (touch) as well. (Also includes illusions – a misperception of an object or event that is real.)	Seeing children or small animals Seeing bugs crawling on the floor or walls Smelling bad odors that others cannot smell Hearing people talking when no one is there
Delusions	Strongly held false belief or opinion, not based on evidence or data. Also includes paranoia, an extreme, irrational distrust of others.	Believing spouse is having an affair Believing relatives long dead are still living Believing a close relative or friend has been replaced by an exact double (<i>Capgras syndrome</i>) Believing food or medicine is poisoned Believing that there are strangers are in the house
Aggression	Hostile, injurious, or destructive behavior or attitude.	Choking, hitting, biting, spitting Verbal abuse

Agitation	Emotional or physical restlessness.	Pacing Hand wringing Inability to “get settled” Constant repeating of words or phrases
Apathy	Lack of interest or concern regarding matters of usual importance.	Decreased social interaction Lack of drive for normal activities Maintenance of ability to enjoy activities once started (versus depression)
Depression	Condition of feeling sad or despondent	Inability to enjoy activities Disturbances of sleep, eating, and other normal activities
Anxiety	Intense apprehension, uncertainty, or fear caused by anticipation of a threatening event or situation.	Asking the same questions repeatedly Being angry or fearful when caregiver is not present

MANAGING BEHAVIORAL SYMPTOMS WITHOUT MEDICATION

It may be possible to reduce the frequency and severity of behavioral symptoms in LBD without medications. For example, new behavioral symptoms or a worsening of symptoms may be caused by physical reasons such as injuries, fever, urinary tract or pulmonary infections, pressure ulcers (also called bed sores), and constipation. Caregivers and physicians should check for these causes before prescribing medication to control behavioral symptoms. When these issues are properly treated, behavioral symptoms often decrease.

Sometimes the medications used to treat other LBD symptoms or other diseases will increase behavioral problems. For example, over-the-counter sleep aids, bladder control medications, and dopaminergic drugs used to treat the motor symptoms of LBD (such as tremors, shuffling walk, and stiffness in arms or legs) can cause confusion, agitation, hallucinations, and delusions. Similarly, benzodiazepines, which are sedative medications typically given to treat anxiety, can actually lead to increased anxiety or worsen cognition in people with LBD. Consult with your loved one’s physician about the possibility of eliminating these medications or reducing their dose.

Because people with LBD are not able to explain why they are frustrated, frightened, or feeling overwhelmed, they may exhibit behavioral symptoms as an expression of these feelings. Caregivers can help to control these feelings (and resulting behavioral symptoms) by reducing sources of stress and anxiety in the home environment. For example, people with LBD do best with simple tasks and consistent

schedules. They benefit from regular exercise and need adequate sleep. Also, excess environmental stimuli like noise or large crowds may make people with LBD feel overwhelmed. Reassuring the person with LBD or offering distractions can prevent behavioral problems when something upsetting happens.

It can be hard for families and people with LBD to cope with hallucinations and delusions. However, hallucinations and delusions can be very real to the people with LBD who experience them. Because people with LBD can lose their ability to evaluate facts and follow a rational argument, you may not be able to reason with them or prove that they are mistaken. For some people with LBD the more you try to prove that a hallucination or delusion is not true, the more agitated and anxious the person will become. It is best to try to respond to the concerns or emotions the person with LBD is expressing. It is worth noting, however, that some people with LBD will be able to recognize that the hallucinations are not real; in this circumstance no behavioral or medical intervention may be necessary.

People with LBD often mirror the feelings and emotions of people around them. Remember that people with LBD are not irritable or anxious on purpose. By keeping calm, understanding the other person's feelings, and offering reassurance caregivers can help to control or avert behavior problems. Additional tips on handling behavior problems can be found on LBDA's website in the article Understanding Behavioral Changes in Dementia.

MEDICATIONS TO TREAT BEHAVIORAL PROBLEMS IN LBD

Medications called cholinesterase inhibitors, developed for treating Alzheimer's disease, are used for treating LBD's cognitive symptoms and, for some people with LBD, reducing behavioral symptoms as well. Cholinesterase inhibitors increase brain levels of acetylcholine, a chemical important for memory and learning. In LBD and other dementias acetylcholine is in short supply. Having more acetylcholine in the brain improves attention and alertness and may lessen behavioral symptoms like hallucinations.

There are three cholinesterase inhibitors currently available: donepezil (Aricept), rivastigmine (Exelon), and galantamine (Razadyne). While these drugs have been approved by the U.S. Food and Drug Administration to treat dementia in Alzheimer's disease, only rivastigmine has been approved to treat Parkinson's disease dementia (one of the LBDs). It is not clear if one of these medications is better for people with LBD than the others. They all improve cognitive and behavioral symptoms and usually do not significantly increase symptoms of parkinsonism.

In one study of Parkinson's disease dementia, a disorder very similar to dementia with Lewy bodies, rivastigmine was associated with a mild increase in tremor in some patients. These medications can have some side effects (most commonly gastrointestinal upset) and may not help behavioral problems in all people with LBD. However, these medications can be a good first choice to treat behavioral symptoms. It is important to note that the use of cholinesterase inhibitors is a long-term treatment strategy for behavioral symptoms and benefits are not immediately observed.

WHAT TO DO WHEN SYMPTOMS DO NOT GO AWAY

Cholinesterase inhibitors do not always help behavioral symptoms. And sometimes reassurance and distraction do not work. What options are available for people with LBD who still have hallucinations or are aggressive? The answer depends on the type and severity of behavioral symptoms.

If a person's hallucinations are not disturbing, or if they are not in danger harming themselves or others, then it may be better to not treat them. However, if the hallucinations are very disturbing or if there is a fear that the person may hurt themselves or others, then additional help is needed.

The best place to go for help is the physician who regularly treats the person's LBD symptoms, usually a neurologist. This physician is familiar with the history of the person's illness, what medications he or she is currently taking, and how he or she reacted to other medications in the past. For cases where behavioral problems are especially difficult to manage, even for a neurologist, consultation with a geriatric psychiatrist is recommended.

ANTIPSYCHOTIC MEDICATIONS

In diseases such as schizophrenia, behavioral symptoms like hallucinations and delusions can be controlled using antipsychotic medications (also called neuroleptics). But in LBD, using antipsychotic medications can be problematic.

We do not know why, but many people with LBD who are treated with antipsychotic medications have very severe reactions. Their cognitive symptoms can become worse and they may appear more sedated. In addition, they may have increased symptoms of parkinsonism. Also, in rare cases, antipsychotic medications may cause a condition called "neuroleptic malignant syndrome" (NMS), which causes severe fever, muscle rigidity and may lead to kidney failure and death. So physicians must be very careful when prescribing antipsychotic medications for someone with LBD.

There are two types of antipsychotic medications: the typical (or traditional) antipsychotics and the newer, atypical antipsychotics.

The typical antipsychotics were the first antipsychotics developed and should NOT be prescribed for people with LBD. Typical antipsychotics include:

- chlorpromazine (Thorazine)
- droperidol (Inapsine)
- fluphenazine (generic only)
- haloperidol (Haldol)
- loxapine (Loxitane)
- molindone (Moban)
- perphenazine (generic only)
- pimozide (Orap)
- thioridazine (generic only)
- thiothixene (Navane)
- trifluoperazine (Stelazine)

The newer or atypical antipsychotics may be helpful for people with LBD if used conservatively. Atypical antipsychotics include the following medications. (**NOTE:** Many LBD experts prefer *quetiapine* or *clozapine* to control difficult behavioral symptoms.)

- aripiprazole (Abilify)
- clozapine (Clozaril)
- fluoxetine & olanzapine (Symbyax)
- iloperidone (Fanapt)
- olanzapine (Zyprexa)
- paliperidone (Invega)
- quetiapine (Seroquel)
- risperidone (Risperdal)
- ziprasidone (Geodon)

Clozapine requires frequent blood tests to monitor for the development of potential blood problems. Both quetiapine and clozapine should be given at the lowest dose possible and for the shortest length of time possible to control symptoms.

Some atypical antipsychotic medications (like olanzapine and risperidone) should be avoided if possible, because they have higher incidences of side effects, such as increased parkinsonism, sedation, and orthostatic hypotension. Ask your loved one's physician about possible side effects on motor function before he or she prescribes an atypical antipsychotic medication.

Caregivers should note that several years ago the U.S. Food and Drug Administration (FDA) issued a warning that all antipsychotic medications, both atypical and typical, increase the risk of death in elderly patients with dementia (this includes people with LBD). Doctors and families should discuss the risks associated with antipsychotic medication use, including the side effects of the medication, against the risks of potential physical harm and distress to the patient or caregivers as a result of behavioral symptoms. Caregivers should contact the doctor about any side effects they observe that do not go away within a few days.

GOING TO THE EMERGENCY ROOM

People with LBD sometimes require emergency care. This may be because of behavioral symptoms or another reason, such as a fall or a heart attack. Caregivers should be prepared for emergencies ahead of time, by asking the physicians who treat their loved ones for copies of the patient's medical history and medication list and bringing these to the emergency room.

Many emergency room physicians are not familiar with LBD or its standard treatments and medication sensitivities. Caregivers can download copies of the LBD Medical Alert Wallet Card and print copies of Treating LBD Psychosis in advance and provide them to emergency room physicians. (Physicians can also access this directly at www.lbda.org/go/ER.) They should also ask emergency room physicians to contact the physician who regularly treats their loved ones' LBD.

If the emergency room physicians want to give an antipsychotic medication to a LBD patient, they should warn caregivers about the possibility of a severe reaction.

YOU ARE NOT ALONE

Behavioral symptoms such as hallucinations, agitation, and aggression are often the worst part of LBD. In the most difficult situations remember to:

- Remain calm
- Respond to the thoughts or feelings that created the behavior
- Provide reassurance to your loved one
- Be able to call on friends or family members for immediate assistance
- Leave the room or the house, if you can do so safely
- Return later, when the situation has calmed down
- And, if necessary, dial 911 in case of emergency

Remember that you are not alone in dealing with LBD. Seek out support from family and friends. You can get help from other people coping with LBD through local support groups and the online LBD community.

ANSWERS TO FREQUENTLY ASKED QUESTIONS

It seems that my mother's hallucinations are worse when she has not slept well. What can I do?

It is not your imagination. Lack of sleep may increase confusion and behavioral problems in people with LBD. Sleep problems including sleep apnea, restless leg syndrome and REM sleep behavior disorder are common in LBD. These sleep problems can keep the person with LBD and his or her caregiver from getting sleep.

Often, these sleep problems can be improved without medications. Increasing daytime activities and avoiding naps (one benefit of senior activity centers) can promote better sleep. In addition, people with dementia should not consume alcohol, caffeine, chocolate or coffee late in the day. Some over-the-counter medications can also affect sleep, these should be reviewed with your mother's physician.

If these non-medication interventions fail to work you may want to ask your mother's physician about what can be done to treat her sleep problems. The doctor may recommend a prescription medication to help your mother sleep at night.

My husband's doctor wants him to start taking a drug called memantine. Will this affect his behavioral symptoms?

Memantine (brand name Namenda) acts by blocking a brain chemical called glutamate, which appears to be overactive in the brains of people with dementia. By blocking the glutamate, memantine may help to improve cognitive function. Memantine has a slightly different method of action than cholinesterase inhibitors, so both medications can be used at the same time.

Memantine was approved for use in the United States in 2003 and there have been several studies reporting its use in people with LBD. The most recent research shows memantine may be beneficial to some people with LBD, particularly for problematic behaviors. If your husband is not taking a cholinesterase inhibitor, you should try these medications first. If he is already on a cholinesterase inhibitor, your husband's physician may suggest a trial of memantine. As with all new medications, you will need to monitor your husband closely and notify his physician if behavioral symptoms worsen.

During a respite stay at a local nursing facility, my wife was given diazepam to calm her down and help her sleep. When I returned she was in terrible shape – alternating between being highly agitated and almost unresponsive. What happened?

Like many medications, benzodiazepines like diazepam (brand name Valium) affect people with LBD differently than younger people without dementia. Benzodiazepines are sedating, but someone with LBD may actually experience this 'paradoxical effect' of alternating sedation and agitation.

Before you schedule another respite stay for your wife, try to find an assisted living or nursing facility that specializes in dementia care. Also, make sure that the physician who normally cares for your wife's LBD is in contact with the medical director of the respite facility. He or she can provide guidance to the facility staff on dealing with your wife's sleep difficulties and behavioral problems.

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 judgment regarding the content and use of this information.