Understanding Lewy Body Dementia

Lewy body dementia (LBD) is a brain disorder that impairs thinking, movement, sleep and behavior. It also affects autonomic body functions, such as blood pressure control, temperature regulation, and digestion.

Lewy body dementia is not a rare disease. An estimated 1.3 million individuals and their families are touched by LBD in the United States alone. Because LBD symptoms may closely resemble other more commonly known diseases like Alzheimer’s and Parkinson’s, it is currently widely under-diagnosed. LBD is an umbrella term for two related diagnoses. It refers to both ‘Parkinson’s disease dementia’ and ‘dementia with Lewy bodies.’ The presenting symptoms differ, but reflect the same underlying biological changes in the brain. Over time, people with both diagnoses will develop very similar cognitive, physical, sleep, and behavioral symptoms.

How to Use this Glossary

This glossary provides helpful information to Lewy body dementia (LBD) families about medications used to treat cognitive, motor, mood or behavioral disorders. The glossary is divided up into sections to make it easier to find what you are looking for.

- **Section 1: Medication Sensitivities** should be read first. It provides an important overview about potentially severe sensitivities to medications used to treat hallucinations or other LBD-related behavioral problems.
- The next part, **Section 2: Medications**, alphabetically lists generic drugs (and corresponding brand names) that are used to treat symptoms of LBD, Alzheimer’s disease and Parkinson’s disease. **NOTE:** Some of these individual drugs should be avoided in Lewy body dementia, but are included here for informational purposes only.
- Lastly, **Section 3: Medication Classes and Related Terms**, defines medication types that fall into the same ‘class’ because they have similar chemical structures or mechanism of action. **NOTE:** Some of these classes of drugs should be avoided in Lewy body dementia, but are included here for informational purposes only.

To learn more about treating symptoms of LBD, please visit LBDA’s website:

- For LBD families: [http://www.lbda.org/content/treatment-options](http://www.lbda.org/content/treatment-options)
- For healthcare providers: [http://www.lbda.org/content/therapeutics](http://www.lbda.org/content/therapeutics)
Section 1: Medication Sensitivities

Some people with LBD are extremely sensitive, or may react negatively, to certain medications used to treat Alzheimer’s or Parkinson’s disease, as well as several over-the-counter medications. There are no definitive indicators as to whether a person with LBD will respond well or poorly to any particular medication. For that reason, treatment can be a delicate balancing act to improve certain LBD symptoms without worsening others.

One of the largest LBD treatment challenges is managing behavioral problems, such as hallucinations, delusions or agitation. Antipsychotics are medications used to treat hallucinations or other serious mental disorders like schizophrenia or bipolar disorder. People with LBD commonly experience severe sensitivity to these medications. Side effects include increased confusion, worsened parkinsonism, extreme sleepiness and low blood pressure that can result in fainting (orthostatic hypotension).

While traditional (or typical) antipsychotic medications, e.g., haloperidol and thioridazine, have been commonly prescribed for individuals with Alzheimer’s for disruptive behavior, these medications can affect the brain of an individual with LBD differently, sometimes causing severe side effects. For this reason, traditional antipsychotic medications like haloperidol which block the brain chemical, dopamine, should be avoided.

Some newer ‘atypical’ antipsychotic medications like risperidone may also be problematic for someone with LBD because they still strongly block dopamine. Some LBD experts prefer quetiapine or clozapine, which work differently from the other antipsychotics. If quetiapine is not tolerated or is not helpful, clozapine should be considered, but requires ongoing blood tests to assure a rare but serious blood condition does not develop.

Therefore, hallucinations, delusions and agitation must be treated very conservatively, using the lowest doses possible under careful observation for side effects. Again, those side effects include increased confusion, worsened parkinsonism, extreme sleepiness and low blood pressure that can result in fainting (orthostatic hypotension). Caregivers should contact the doctor if these side effects continue after a few days.

WARNING: In rare cases, a potentially deadly condition called neuroleptic malignant syndrome can occur with the use of any antipsychotic medication. Symptoms of this condition include high fever, muscle rigidity, and muscle tissue breakdown that can lead to kidney failure. Report these symptoms to your doctor immediately or seek emergency medical care.
The U.S. Food and Drug Administration (FDA) requires a black box warning on all antipsychotic medications, due to an increased risk of death in elderly people with any form of dementia. LBD families and doctors should weigh the risk of antipsychotic use against the risks of physical harm and distress that may occur as a result of untreated behavioral problems.

Medications to treat other LBD symptoms, including some over-the-counter medications for insomnia or colds, can cause side effects like confusion, sedation, agitation, or even make existing symptoms, like hallucinations and parkinsonism, worse. Report any concerning reactions to new medications to the prescribing physician promptly.

For more information on treating LBD behavioral problems, visit http://www.lbda.org/content/treatment-behavioral-symptoms-when-consider-antipsychotic-medications-lbd
Section 2: Medications

Medications below are listed alphabetically by generic name, with related brand names in parentheses.

**alprazolam (Xanax):** A medication in the benzodiazepine class, used to treat anxiety and panic disorders. Shorter acting than clonazepam, but can cause sedation, confusion or paradoxical agitation in people with LBD.

**amantadine (Symmetrel):** Used to treat dyskinesia (abnormal involuntary muscle movements) in Parkinson’s disease and other motor disorders. Also used to prevent and treat respiratory infections caused by certain forms of influenza. May worsen cognitive impairment in individuals with LBD and should be avoided.

**amphetamine with dextroamphetamine (Adderall):** Psychostimulant medication whose effects can include improved concentration, decreased sensory overstimulation, decreased irritability and decreased anxiety. It is commonly used to treat ADHD and narcolepsy. May be helpful in treating excessive daytime sleepiness in individuals with LBD.

**armodafinil (Nuvigil):** Psychostimulant medication used to treat excessive sleepiness caused by narcolepsy or shift work sleep disorder. May be helpful in treating excessive daytime sleepiness in individuals with LBD.

**botulinum toxin:** Used to weaken certain muscles by interfering with the nerve to muscle signal. Administered by injection in or near the salivary gland in the cheek or under the jaw to treat drooling in Parkinson’s disease and LBD. It can be an effective alternative to oral medications with anticholinergic properties, which can exacerbate confusion.

**buspirone (Buspar):** Medication mainly used to treat anxiety disorders. May be helpful in reducing anxiety, obsessions or compulsions in individuals with LBD.

**carbamazepine (Tegretol, Carbatrol):** Anticonvulsive and mood stabilizing medication used primarily to treat epilepsy and bipolar disorder. Also used to treat agitation in individuals with dementia.

**carbidopa (Lodosyn):** Medication used together with levodopa, which treats the motor symptoms of Parkinson’s disease and other parkinsonian disorders, such as tremors, stiffness and slowness of movement. Functions by allowing higher levels of levodopa to enter the brain and also can help reduce levodopa’s side effects.
carbidopa/levodopa (Sinemet): Combination of two medications used to treat motor symptoms of Parkinson’s disease and Lewy body dementia, such as tremors, stiffness and slowness of movement. The addition of carbidopa prevents levodopa from being broken down before it reaches the brain, allowing for a lower dose of levodopa and minimizing any nausea or vomiting.

chlordiazepoxide (Chlordiazepoxide): Medication used as a sedative and hypnotic, often as a sleeping aid for insomnia or as a sedative before minor medical treatment. This medication has not been extensively studied in individuals with LBD and daytime sedation is a potential side effect. Increased nighttime confusion may occur with any sedative when treating insomnia in those with LBD.

citalopram hydrobromide (Celexa): A type of selective serotonin reuptake inhibitor (SSRI) antidepressant medication used in the treatment of depression and associated mood disorders such as panic disorder and anxiety. This medication works by restoring the balance of neurotransmitters in the brain.

clonazepam (Klonopin): Medication mainly used to treat anxiety or epilepsy. Also helpful in managing symptoms of REM sleep behavior disorder, a sleep disorder common in LBD. However, clonazepam and other types of benzodiazepines may potentially aggravate confusion and sleepiness in elderly people with LBD. Low and cautious doses are advised.

clozapine (Clozaril): An atypical antipsychotic medication used mainly to treat schizophrenia. It is helpful in the treatment of psychosis in Parkinson's disease. Requires ongoing blood tests to assure a rare but serious blood condition does not develop. Monitoring for low blood pressure is recommended.

diazepam (Valium): Benzodiazepine drug used to treat anxiety, muscle spasms and seizures. May produce sedation, confusion or paradoxical agitation in people with LBD and should be avoided. See clonazepam.

dimenhydrinate (Dramamine): Over-the-counter antihistamine used to treat motion sickness and nausea. May produce confusion and hallucinations in people with LBD and should be avoided.

diphenhydramine (Benadryl, Nytol, Unisom): Over-the-counter antihistamine mainly used as an antihistamine and also for its sedative properties. It is sometimes used to counter the motor-related side effects of some antipsychotic drugs. May produce confusion and hallucinations in people with LBD and should be avoided.
donepezil (Aricept): Acetylcholinesterase inhibitor mainly used to treat mild to moderate dementia in Alzheimer’s disease. Medications in the same class are used in the treatment of LBD cognitive symptoms, and may also be helpful in treating hallucinations and other psychiatric symptoms of LBD.

entacapone (Comtan): A COMT inhibitor used in combination with carbidopa/levodopa to prolong the action of carbidopa/levodopa and treat motor symptoms in Parkinson’s disease.

fludrocortisone acetate (Florinef): Medication used to treat orthostatic hypotension or low blood pressure, a common LBD symptom of dysfunction in the autonomic nervous system.

fluoxetine (Prozac): SSRI antidepressant used to treat mood disorders such as depression, panic attacks and other anxiety disorders. This medication works by restoring the balance of neurotransmitters in the brain. Due to known interactions with other drugs and slowed metabolism in older adults, this SSRI antidepressant is not often used in elderly adults.

fluphenazine (Modecate): Potent traditional (typical) antipsychotic drug mainly used to treat schizophrenia and bipolar disorder. May also be used to treat psychotic symptoms such as delusions and hallucinations in other conditions. **WARNING**: Fluphenazine and all traditional (typical) antipsychotic drugs are known to have severe side effects in individuals with LBD, and should be avoided.

galantamine (Razadyne): Acetylcholinesterase inhibitor mainly used to treat mild to moderate dementia caused by Alzheimer’s disease. Medications in the same class are used in the treatment of LBD cognitive symptoms, and may also be helpful in treating hallucinations and other psychiatric symptoms.

glycopyrrolate (Robinul): Anticholinergic medication which reduces stomach acid and saliva. May also reduce sweating as a side effect. Low and cautious doses are advised due to cognitive and behavioral side effects of confusion and hallucinations.

haloperidol (Haldol): Traditional (typical) antipsychotic medication that interferes with the effects of neurotransmitters in the brain. It primarily functions by blocking receptors on neurons for the neurotransmitter dopamine. **WARNING**: Haloperidol and all traditional (typical) antipsychotic drugs are known to have severe side effects in individuals with LBD, and should be avoided.
**levodopa (Dopar, Larodopa)**: Medication used to treat the symptoms of Parkinson’s disease such as tremors. It acts on the brain by increasing levels of the neurotransmitter dopamine in the brain. See carbidopa/levodopa.

**lorazepam (Ativan)**: Benzodiazepine drug mainly used to treat anxiety and to counter the effects of nausea in chemotherapy. May cause paradoxical agitation in people with LBD. Low and cautious doses are advised.

**melatonin**: Naturally occurring hormone responsible for regulating various biological functions such as sleep/wake cycle. It can be available over-the-counter in the form of a supplement, used to treat disorders such as insomnia. May be helpful in managing REM sleep behavior disorder or insomnia in individuals with LBD.

**memantine hydrochloride (Namenda)**: Medication mainly used for Alzheimer's disease that may protect nerve cells from excessive stimulation by glutamate. Memantine may help with cognition, functional ability and behavioral symptoms in people with LBD.

**methylphenidate (Ritalin)**: Drug commonly used to treat attention deficit hyperactivity disorder (ADHD) that acts as a stimulant of the central nervous system. May be helpful in treating excessive daytime sleepiness in individuals with LBD.

**midodrine (Proamantine)**: Medication which can be used to treat orthostatic hypertension or low blood pressure, a symptom of autonomic nervous system dysfunction in LBD.

**modafinil (Provigil)**: Stimulant-like medication used to treat excessive daytime sleepiness or problems with breathing while asleep. May be helpful in treating excessive daytime sleepiness in individuals with LBD.

**olanzapine (Zyprexa)**: Atypical antipsychotic drug used to treat schizophrenia and bipolar disorder. It has not been shown to be safe or effective in treating hallucinations in Parkinson’s disease, and causes worsened motor function. Olanzapine has a higher incidence of serious side effects in individuals with LBD, such as severe neuroleptic sensitivity reactions, parkinsonism, solemnence and orthostatic hypotension, and should be avoided if possible.

**oxybutynin (Ditropan)**: Anticholinergic medication commonly used to treat bladder control problems. Medications in this class can increase sedation and confusion in a person with LBD.
quetiapine (Seroquel): **Atypical antipsychotic** drug mainly used to treat schizophrenia and bipolar disorder. Some LBD experts prefer quetiapine to other medications in its class to treat behavioral symptoms of LBD since it does not require blood count monitoring. Monitor for low blood pressure.

paroxetine (Paxil): **SSRI antidepressant** used to treat mood disorders such as depression, panic attacks and other anxiety disorders.

pramipexole (Mirapex): **Dopamine agonist** drug used to treat motor symptoms of Parkinson’s disease. May cause sleepiness, hypotension, hallucinations especially in cognitively impaired individuals and the elderly.

rasagiline (Azilect): An **MAO inhibitor** (type B) used to treat the motor symptoms of Parkinson’s disease.

risperidone (Risperdal): **Atypical antipsychotic** drug used mainly to treat schizophrenia. Risperidone has a higher incidence of serious side effects in individuals with LBD, such as severe neuroleptic sensitivity reactions, parkinsonism, sleepiness and orthostatic hypotension, and should be avoided if possible.

rivastigmine (Exelon): An **acetylcholinesterase inhibitor** used to treat dementia. It is also the first treatment for dementia available in a transdermal patch. Medications in the same class are used in the treatment of LBD cognitive symptoms, and may also be helpful in treating hallucinations and other psychiatric symptoms of LBD.

rotigotine (Neupro patch): **Dopamine agonist** drug used to treat motor symptoms of Parkinson’s disease. May cause sleepiness, hypotension, hallucinations especially in cognitively impaired individuals and the elderly.

ropinirole (Requip): **Dopamine agonist** drug used to treat motor symptoms of Parkinson’s disease. May cause sleepiness, hypotension, hallucinations especially in cognitively impaired individuals and the elderly.

selegiline (Eldepryl): An **MAO inhibitor** (type B) used to treat the motor symptoms of Parkinson’s disease.

sertraline (Zoloft): **SSRI antidepressant** used to treat mood disorders such as depression, panic attacks and other anxiety disorders.
thioridazine (Mellaril): Traditional (typical) antipsychotic medication used to treat schizophrenia and symptoms such as hallucinations and delusions. **WARNING:** Thioridazine and all traditional (typical) antipsychotic drugs are known to have severe side effects in individuals with LBD, and should be avoided.

tolcapone (Tasmar): A COMT inhibitor used in combination with carbidopa/levodopa to treat motor symptoms in Parkinson’s disease; this medication requires monitoring of liver function.

trazadone (Desyrel): Serotonin modulator drug used to treat depression. May also be helpful in managing insomnia, but this medication has not been extensively studied in individuals with LBD and daytime sedation is a potential side effect.

valproic acid (Depakote): Used alone or with other medications to treat seizures. Also used to treat mania in bipolar disorder. May be helpful in LBD to reduce behavioral symptoms.

zolpidem (Ambien): Sedative-hypnotic medication used to treat insomnia. This medication has not been extensively studied in individuals with LBD and daytime sedation is a potential side effect.
Section 3: Medication Classes and Related Terms

**acetylcholine**: Key chemical in neurons (brain cells) that acts as a neurotransmitter, which carries information between two brain cells. It is involved in several functions including cognition, emotion, sensation and arousal. Some of the memory and cognitive symptoms of Alzheimer's disease and Lewy body dementias are commonly attributed to a loss of acetylcholine-producing neurons.

**acetylcholinesterase inhibitor (AChEI)**: Medication that increases the level of acetylcholine in the brain by inhibiting the function of substances which break down acetylcholine. These drugs can decrease some cognitive symptoms of dementia. They may also be used for treatment of agitation and hallucinations. Side effects may include slowed heart rate, lightheadedness, fainting, mild increase in tremor or parkinsonism. Also called cholinesterase inhibitor or anticholinesterase.

**anticholinergic**: A medication that reduces the effect of acetylcholine in the brain. They are often used to reduce cramps and spasms in smooth muscles such as the stomach, intestines, or bladder, and also tremors in the limbs and body. Some allergy medicines (e.g., diphenhydramine) also have high anticholinergic activity. Drugs in this class may worsen cognitive impairment, confusion, and hallucinations in individuals with LBD and should be avoided if possible.

**anticholinesterase**: See acetylcholinesterase inhibitor.

**antidepressants**: Medication or substance used to treat depression. The most common classes of antidepressant drugs include tricyclics, SSRIs, and SNRIs. Tricyclic antidepressants can worsen hallucinations and sedation, especially in elderly and cognitively impaired individuals. Other symptoms include cardiac rhythm disturbances and dry mouth.

**antipsychotic drug**: Medication which can treat hallucinations, delusions and agitations. Traditional (or typical) antipsychotic medications are also known as neuroleptic drugs. Individuals with LBD can have severe neuroleptic sensitivity to antipsychotic drugs, with possible worsening of symptoms and increased mortality rate. See atypical antipsychotic drug and traditional (typical) antipsychotic drug.

**anxiolytic**: Medication used to treat the symptoms of anxiety.
**atypical antipsychotic drug:** Newer generation of antipsychotic drugs differing from traditional (typical) antipsychotic drugs in their pharmacological action. Drugs in this class carry a black box warning from the U.S. Food and Drug Administration, indicating that for older adults with dementia, the medication carries an increased risk of serious or even life-threatening adverse effects. Despite this risk, due to the presence of visual hallucinations in LBD, there may be a need to prescribe this type of medication. Physicians should discuss the risks and benefits of these types of medications, so that individuals with LBD and caregivers can consider issues of quality of life against the risks associated with these medications.

**benzodiazepine:** Drugs that enhance a neurotransmitter involved in motor control. These drugs have various properties, such as anti-anxiety, hypnotic, muscle relaxant, anti-convulsant, or amnesiac. May produce sedation and confusion in people with LBD and should be avoided.

**black box warning:** The strongest warning issued by the U.S. Food and Drug Administration, required to be included on prescription package inserts when medical studies indicate a prescription drug carries a significant risk of serious or even life-threatening adverse effects. It is so named for the black border that surrounds the text of the warning.

**cholinesterase:** Enzyme responsible for breaking down the neurotransmitter acetylcholine.

**cholinesterase inhibitor:** See acetylcholinesterase inhibitor.

**COMT inhibitors:** Medication which inhibits the action of the enzyme Catechol-O-methyl transferase (COMT). COMT is responsible for degrading the neurotransmitters dopamine, epinephrine, and norepinephrine.

**depressant:** Medication or substance reducing the activity of the central nervous system, resulting in calmness, slowed breathing, reduction in anxiety, muscle relaxation, and sleepiness. Examples of depressants include benzodiazepines, alcohol, anesthetics, and anticonvulsants. Also known as a sedative or sedative-hypnotic.

**dopamine:** One of the primary neurotransmitters in the brain, it is involved in several functions including movement, cognition, motivation, and pleasure. The motor symptoms of Parkinson’s disease and Lewy body dementias are commonly attributed, at least in part, to a loss of dopamine-producing neurons.

**dopamine agonist:** Medication which mimics the action of the neurotransmitter dopamine, activating dopamine receptors. They are often used to treat Parkinson’s disease. As this class of drugs has side effects, especially drug-induced psychosis, it should be avoided if possible in LBD.
glutamate: Main excitatory neurotransmitter in the brain.

MAO inhibitor: Class of drugs used to treat motor symptoms or depression in Parkinson's disease by inhibiting the breakdown of dopamine. MAO inhibitors may worsen cognition and should be avoided if possible in LBD.

mood stabilizer: Medication typically used to treat symptoms such as mania and agitation in bipolar disorder.

neuroleptic: Term referring to the effects of antipsychotic drugs on a person, especially on their cognition and behavior.

neuroleptic drugs/neuroleptics: See antipsychotic drug.

neuroleptic malignant syndrome (NMS): Rare neurological disorder caused by an adverse reaction to neuroleptic drugs, characterized by high fever, unstable blood pressure, muscular rigidity, and autonomic dysfunction. In severe cases, NMS can be fatal. People with LBD who are treated with neuroleptics are at risk for developing NMS.

neuroleptic sensitivity: An adverse reaction or event to a neuroleptic drug such as Parkinson-like side effects including rigidity, immobility and difficulties with posture. Individuals with Lewy body dementias have particularly high, sometimes fatal, neuroleptic sensitivity.

neurotransmitter: Chemical that transfers from one neuron to another cell, causing it to either increase or decrease the activity of the receiving neuron. It is thought to be the primary way that neurons communicate with each other in the brain.

NMDA antagonist: Class of drugs which inhibit the action of N-methyl d-aspartate (NMDA). They are mainly used as anesthesia for animals and sometimes for humans. Certain NMDA receptor antagonists such as memantine can be used to treat dementia.

sedative: See depressant.

SNRI (serotonin-norepinephrine reuptake inhibitor): Class of antidepressant which increases levels of both serotonin and norepinephrine. It used to treat depression and other mood disorders such as anxiety and obsessive-compulsive disorder.

SSRI (selective serotonin reuptake inhibitor): Common class of antidepressant used to treat depression and anxiety. SSRIs function by reducing the reabsorption of serotonin by certain nerve cells in the brain.
**stimulant:** Class of medication used to increase alertness and awareness. Stimulant effects commonly include increased heart rate, blood pressure, and respiration rate.

**traditional (or typical) antipsychotic medications:** An older generation of antipsychotic medications used to treat hallucinations, delusions and agitations by blocking dopamine in the brain. Drugs in this class carry a black box warning from the U.S. Food and Drug Administration, indicating that for older adults with dementia, the medication carries a significant risk of serious or even life-threatening adverse effects. **WARNING:** Due to the risk of severe neuroleptic sensitivity reactions, neuroleptic malignant syndrome, parkinsonism, somnolence and orthostatic hypotension, these medications should be avoided in LBD.

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Sources:
# Appendix: Medications Listed by Brand Name

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<th>Brand Name</th>
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To learn more about LBD, visit www.lbda.org

LBD Caregiver Link:
1-800-LEWYSOS
1-800-539-9767

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