UNDERSTANDING YOUR DIAGNOSIS

Lewy Body Dementia

Also called Major or Mild Neurocognitive Disorder with Lewy Bodies

A brain disease with good days and bad days, seeing things, and stiff movement. Some antipsychotic medicines are dangerous here.

HOW COMMON	OFTEN STARTS	TREATABLE	YOU ARE NOT ALONE
About 1 in 20 dementia cases	Usually between 50 and 85	Yes - symptoms can be eased	Over 1 million US adults

What this is

- Lewy body dementia is a brain disease caused by a protein that builds up and damages brain cells over years.
- It brings thinking changes, seeing things that are not there, stiff slow movement, and acting out dreams at night.
- SAFETY: some antipsychotic medicines cause a severe, sometimes deadly reaction in this disease. Tell every doctor.
- This sheet is for you and your care partner. Both of you need to know that medicine warning by heart.

What it can look and feel like

- Thinking swings from hour to hour and day to day. Good days and bad days are the hallmark, not a mood.
- You may stare into space, drift off during the day, or lose the thread mid-sentence, then come right back.
- You may see people, children, or animals that are not there. Early on they often are not frightening at all.
- Acting out dreams, kicking, shouting, or falling out of bed can start **10 years** before anything else shows.
- Movement gets slow and stiff, balance gets worse, and falls tend to come early rather than late in this illness.
- Judging distance, copying a shape, or reading a clock face gets hard well before memory really slips.
- Standing up may bring dizziness or fainting, and constipation and a lost sense of smell are common too.

What is happening in your brain and body

- A protein called alpha-synuclein clumps up inside brain cells and slowly stops them from working properly.
- Acetylcholine, a brain chemical for attention and memory, drops sharply here. Medicines that raise it help a lot.
- Dopamine, the chemical for smooth movement, also falls, which brings the stiffness and the slow, shuffling walk.
- The brainstem switch that keeps your body still while you dream gets damaged, so the dreams get acted out.
- Because both chemicals are already low, medicines that block dopamine hit this brain far harder than any other.

What can make it more likely

- The cause is not fully known. It is not something you did, and it is not brought on by stress or by worry.
- Age is the main factor, and the illness is somewhat more common in men than it is in women.
- Some genes raise the chance, and it can run in families, though most cases have no clear family link at all.
- Acting out dreams for years is the strongest early warning sign we know of, sometimes decades ahead of the rest.

What to expect

- This illness moves faster than Alzheimer's, often over **5 to 8 years**, with real ups and downs along the way.
- The right medicines can genuinely help thinking, alertness, and hallucinations, often more than in Alzheimer's.
- A sudden worsening usually means something else: an infection, dehydration, or a new medicine. Get it checked.
- Bringing in palliative care early is about comfort and support, not giving up. Families often wish they had sooner.

What helps

Treatment works. Most people get better.

Talking therapies

- Learning about the swings, the hallucinations, and the medicine danger is the highest-value thing you can do.
- For hallucinations, turn up the lights, take down mirrors, and calmly redirect rather than argue about what is real.
- **Cognitive stimulation therapy**, about 14 group sessions of themed activity and talk, helps in milder stages.
- **Talk therapy** adapted with shorter sessions and written reminders helps low mood and worry early on.
- **Care partner programs** such as START lower care partner depression and can delay a move into a care home.

Medicines

- **Rivastigmine**, as a pill or a skin patch, is first choice and often helps thinking and hallucinations here.
- DANGER: **antipsychotics** such as haloperidol can cause severe stiffness, deep confusion, and death in this disease.
- If hallucinations become dangerous, only low-dose quetiapine or clozapine should be tried, and only with consent.
- **Melatonin** at bedtime is first choice for acting out dreams. Clonazepam works but adds falls and grogginess.
- Parkinson's medicines are used carefully and in small amounts, since they can worsen seeing things and dizziness.

Everyday things that help

- Make the bedroom safe tonight: lower the bed, clear the nightstand, pad sharp corners, and secure any firearms.
- Check blood pressure sitting and then standing. Dizziness on standing causes many of the falls in this illness.
- Clear out sleep aids, older allergy pills, bladder pills, and calming medicines. They badly worsen confusion.
- Wear a medical alert bracelet naming this diagnosis and the antipsychotic warning, and get it into the chart.
- Keep routines steady, and save the hard tasks for the good hours. Pushing through a bad hour rarely works.

Get help right away if

- Tell every doctor and every emergency room: antipsychotics can cause a severe or fatal reaction in this disease.
- Go to the emergency room for new stiffness, high fever, or a drop in alertness after any new medicine.
- If you or your care partner think about ending life, call or text **988** now, or go to the emergency room.

Questions to ask your care team

- *Which antipsychotic medicines are unsafe for me, and is that written in my chart?*
- *What should we hand emergency room staff so they do not give a dangerous medicine?*
- *Would rivastigmine or melatonin help me, and what side effects should we watch for?*
- *Which of my current medicines should we stop because they worsen confusion?*

Where this information comes from

Alzheimer's Association. (n.d.). *Dementia with Lewy bodies (DLB)*. https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/lewy-body-dementia

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). https://doi.org/10.1176/appi.books.9780890425787

Lewy Body Dementia Association. (n.d.). *What is LBD?* https://www.lbda.org/what-is-lbd/

MedlinePlus. (n.d.). *Lewy body dementia*. U.S. National Library of Medicine. https://medlineplus.gov/lewybodydementia.html

National Institute of Neurological Disorders and Stroke. (n.d.). *Lewy body dementia*. U.S. Department of Health and Human Services. https://www.ninds.nih.gov/health-information/disorders/lewy-body-dementia

National Institute on Aging. (n.d.). *Lewy body dementia: Causes, symptoms, and diagnosis*. U.S. Department of Health and Human Services. https://www.nia.nih.gov/health/lewy-body-dementia/what-lewy-body-dementia-causes-symptoms-and-treatments

NOTE

Sources are listed in APA 7th edition style. This handout is general health information, not medical advice, and it does not replace talking with your own doctor, therapist, or prescriber. Medicine choices and doses are decided with your prescriber. If you are in danger or thinking about hurting yourself, call or text 988 in the United States, or go to your nearest emergency room.