



When 911 Gets Involved

A Gentle Guide for Families Living with Lewy Body Dementia

There may come a day when things escalate.
A delusion becomes fear.
Fear becomes anger.
Anger becomes unsafe.

And you find yourself dialing 911 with
shaking hands.

If that ever happens, please hear this first:
You are not failing.
You are protecting everyone in the room.

Living with Lewy Body Dementia (LBD) can
mean living with:

- vivid hallucinations
- jealousy or paranoia
- misidentification (Capgras Syndrome)
- sudden mood shifts
- dramatic “fluctuations” in clarity

These are neurological symptoms — not
character flaws.

And sometimes, they spill over.

Why LBD Is Different From Alzheimer’s

Many first responders are familiar with
Alzheimer’s disease. Fewer are trained
specifically in Lewy Body Dementia.

That matters.

In LBD:

- Hallucinations happen early and often.
- Delusions can be fixed and intense.
- The person may seem completely lucid
minutes later.
- Certain medications — especially some
antipsychotics — can cause severe
reactions.

This is not stubbornness.

It is brain chemistry.

Sources for deeper reading:

- Lewy Body Dementia Association
- National Institute on Aging
- Mayo Clinic

If You Ever Have to Call 911

Here are a few gentle things you can say when responders arrive:

“My spouse has Lewy Body Dementia.”

“He may seem clear in a few minutes — that’s part of the disease.”

“He is very sensitive to antipsychotic medications.”

“Arguing the delusion may make it worse.”

You are allowed to advocate.

You are allowed to say,

“Certain medications can be dangerous for him.”

You are allowed to ask,

“Can we reduce stimulation?”

Even in crisis.

About Capgras (If This Is Part of Your Story)

Capgras is a neurological misidentification syndrome.

Your loved one may believe:

- You are an impostor.
- You had an affair.
- You are part of a conspiracy.
- Someone is in the house who isn’t.

The fear feels real to them.

Logic rarely fixes it.

This is not personal.

Even when it feels deeply personal.

A Hard Truth (Said Gently)

If you ever feel physically unsafe...

Call.

You can love someone deeply and still need help.

Those two truths can live in the same house.

Looking for additional support?
A free **Emergency Response Kit for Lewy Body Dementia caregivers** — including emergency forms and first responder information — is available at LivingWithLewy.net.

A Simple Crisis Card for Your Wallet

You may want to carry something like this:

- *Cut along dotted lines*
- *Fold along solid line*
- *Laminate, and carry in your wallet*

LEWY BODY DEMENTIA ALERT	
Name: _____	<ul style="list-style-type: none"> • Rapid cognitive fluctuations • Severe sensitivity to antipsychotic medications
Caregiver: _____	
Neurologist: _____	
THIS INDIVIDUAL MAY EXPERIENCE	
<ul style="list-style-type: none"> • Visual hallucinations • Capgras (misidentification of loved ones) • Jealousy or paranoia delusions 	
FOR FIRST RESPONDERS:	
<ul style="list-style-type: none"> • Speak calmly and slowly • Avoid arguing delusions • Limit multiple voices • Consult LBD-aware provider before giving antipsychotics 	
More info: Lewy Body Dementia Association (lbda.org)	

You Are Not Alone in This

Many caregivers never talk about the 911 calls.

But they happen.

You are not weak if it happens to you.

You are navigating a neurological storm without a weather map.

If this has happened in your home,
sit down.

Breathe.

Have some tea.

And remember:

You are not the cause of the delusion.

You are not the enemy.

You are the steady one.

Even when the world inside your house tilts sideways.