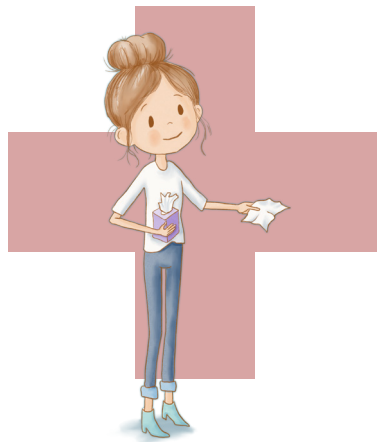


When a Dementia Crisis Escalates

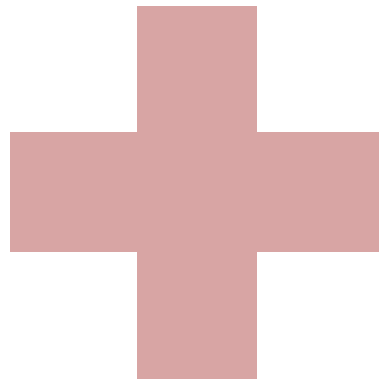


**An Emergency Response Packet for
Lewy Body Dementia Caregivers**

www.LivingWithLewy.net

Practical guidance and support for Lewy Body Dementia caregivers

When a Dementia Crisis Escalates



An Emergency Response Packet for Lewy Body Dementia Caregivers

Includes:

1. A gentle introduction for caregivers
2. A sample letter to first responders
3. A first-responder educational reference sheet
4. A one-page emergency information form (fillable)
5. A wallet-size medical alert card
6. A short caregiver grounding page (post-incident)

Before You Read This

There may come a day when things escalate.

A delusion deepens.
Fear takes hold.
And suddenly, safety becomes a concern.

If you are here because something already happened — please pause.

You did not fail.
You did not overreact.
You are not alone.

This packet exists because Lewy Body Dementia can involve sudden behavioral changes, delusions, and medication sensitivities that are not widely understood in emergency settings.

You are reading this because you care deeply — and because you want to be prepared.

That is not pessimism.
That is love, expressed wisely.

SAMPLE

Thank You Letter to First Responders

[Date]

[Local department name]

Subject: Thank You for Your Assistance on [Date]

To the Officers and First Responders who assisted at our home on [date],

I am writing to thank you for responding to our 911 call on [date] at [address or general location].

I understand that you were called into a challenging and unpredictable situation, and I am grateful for your professionalism and for the care you took to ensure everyone's safety.

My [relationship, e.g., husband / wife / parent], [name], lives with Lewy Body Dementia (LBD). At the time of the call, [he/she/they] was experiencing a severe neurological episode involving confusion and delusional thinking. While the situation was frightening for our family, I recognize that you had to make rapid decisions based on the information available to you in the moment.

I appreciate the role you played during this incident and the service you provide to our community every day.

[optional] I have included a brief educational reference on Lewy Body Dementia that may be helpful for future calls involving dementia-related crises.

Thank you again for your time, your professionalism, and your commitment to public safety.

With sincere appreciation,

[Your full name]

[Relationship to person with dementia]

[City / State, optional]

[Phone or email, optional]

Emergency Response Guide

Prepared as an educational reference to support first responders during dementia-related crisis calls.

Lewy Body Dementia (LBD) vs. Alzheimer's Disease

Why the Difference Matters in Crisis Situations

What Is Lewy Body Dementia (LBD)?

Lewy Body Dementia is a progressive neurodegenerative disorder caused by abnormal protein deposits (alpha-synuclein) in the brain. It affects cognition, movement, behavior, perception, and autonomic function.

It is the **second most common degenerative dementia after Alzheimer's disease.**

Sources:

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

Key Clinical Differences: LBD vs. Alzheimer's

Feature	Lewy Body Dementia	Alzheimer's Disease
Visual hallucinations	Early and vivid	Usually later stage
Delusions	Common and fixed	Less common early
Cognitive fluctuation	Dramatic hour-to-hour changes	Gradual decline
Parkinsonian movement	Common	Typically later
REM sleep behavior disorder	Common	Uncommon
Antipsychotic sensitivity	High risk	Lower risk

Sources:

- Lewy Body Dementia Association Clinical Features
- National Institute on Aging Dementia with Lewy Bodies overview
- Mayo Clinic Lewy Body Dementia overview

Capgras Syndrome in LBD

Capgras Syndrome is a misidentification delusion in which a person believes a loved one has been replaced by an impostor.

In LBD:

- It is neurologically driven.
- It cannot be corrected with logic.
- It often triggers fear, jealousy, or defensive aggression.
- The belief feels absolutely real to the person experiencing it.

Source:

- Lewy Body Dementia Association Behavioral & Psychiatric Symptoms in LBD

+ Critical Medication Warning

Individuals with LBD may have severe or life-threatening reactions to typical antipsychotic medications, including:

- Haloperidol (Haldol)
- Risperidone
- Olanzapine

Possible reactions include:

- Severe rigidity
- Profound sedation
- Worsening confusion
- Neuroleptic Malignant Syndrome (rare but life-threatening)

Medication decisions should ideally involve a neurologist familiar with LBD.

Sources:

- Lewy Body Dementia Association Treatment Guidelines
- Mayo Clinic Lewy Body Dementia treatment cautions

Crisis De-Escalation Considerations for First Responders

When safety allows:

- Speak slowly and calmly.
- Use short, simple sentences.
- Avoid arguing with delusional content.
- Do not attempt reality correction.
- Reduce sensory overload (lights, multiple voices, loud commands).
- Offer reassurance over logic (“You’re safe” vs. “That didn’t happen”).

Understand that:

- A person may appear lucid minutes later.
- Fluctuation is a hallmark of LBD.
- Escalation is often fear-based, not intentional aggression.

Why This Education Matters

As dementia prevalence increases nationwide, first responders will encounter LBD more frequently.

Recognizing the difference between Alzheimer’s disease and Lewy Body Dementia:

- Improves safety outcomes
- Reduces unnecessary escalation
- Prevents medication complications
- Supports families in crisis

Emergency Information

Lewy Body Dementia

Individual's Name:	
Diagnosis:	
Neurologist/Clinic:	
Neurologist Phone:	
Primary Caregiver:	
Emergency Contact Name:	
Emergency Contact Phone:	

Known Symptoms (check all that apply):

- Visual hallucinations
- Delusions / paranoia
- Capgras syndrome
- Severe cognitive fluctuations
- Parkinsonian movement symptoms
- Medication sensitivity

Medication Notes

Certain **antipsychotic medications** may cause severe reactions in LBD.

Medication decisions should ideally involve an LBD-aware provider.

During Crisis, Please Note

- Avoid arguing delusions
- Speak calmly and slowly
- Limit multiple voices
- Reduce sensory stimulation

Wallet-Sized Medical Alert Card

(Front & back, printable with cut lines)

<p>MEDICAL ALERT LEWY BODY DEMENTIA</p> <p>Name: _____</p> <p>Emergency Contact: _____</p> <p>Neurologist: _____</p>	<p>! IMPORTANT FOR FIRST RESPONDERS</p> <ul style="list-style-type: none">• May experience delusions or misidentification• Rapid cognitive fluctuations are common• Avoid typical antipsychotics if possible• Calm reassurance is more effective than logic <p>More info: Lewy Body Dementia Association (lbda.org)</p>
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Instructions:

- Print page
- Add name and contact information
- Cut out along solid lines
- Fold along dashed line
- Laminate

After the Crisis

If first responders have just left your home...

Sit down.

Put your feet on the floor.

Breathe slowly.

You may feel:

- shaken
- guilty
- numb
- relieved
- embarrassed
- heartbroken

All of that is normal.

Calling for help does not mean you stopped loving them.
It means you were protecting both of you.

You do not need to decide anything today.

Tea and rest first.

You are allowed to recover too.

Living With Lewy provides caregiver education, safety resources, and compassionate support for families navigating Lewy Body Dementia. Learn more or connect with our caregiver community at LivingWithLewy.net or on Facebook, Instagram, and Pinterest.



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