

**Non-drug Approaches for Care Partners to
Use When a Loved One Living with LBD
has Behavioral Changes**

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Behavioral and Mood Changes



Behavioral and Mood Changes

- Experienced by most people living with LBD
- Can begin very early in the disease, show up later, or both
- Vary from person to person, from benign to intrusive to disturbing
- Some types are more common than others
- Greatly increase care partner burden

Behavioral and Mood Changes

- **Auditory hallucinations** — false perceptions of sound such as buzzing, knocking, background music, or people speaking
- **Visual hallucinations** — clearly seeing something that isn't there, often with great detail
- **Feelings of presence** — vivid fleeting sensations, typically lasting only a few seconds, that someone else is present, perhaps off to the side or behind, but not visible
- **Illusions** — visual misperceptions; things are wrongly perceived or interpreted by the senses

Behavioral and Mood Changes

- **Delusions** – fixed false beliefs that occur when LBD interferes with a person's thinking
 - ***Paranoia*** – irrationally feeling harmed or persecuted resulting in suspicion, fear, or jealousy with inappropriate, even violent behavior
 - ***Capgras syndrome*** – a delusional belief that a person - often a spouse, other close relative, or a friend - has been replaced by an identical double or imposter
 - ***Reduplicative paramnesia*** – the delusion that there are two or more identical people, places, or things

Behavioral and Mood Changes

- **Mood disorders** – LBD interferes with a person's emotional stability.
 - **Depression** – feelings of sadness, hopelessness, discouragement, or irritability for extended periods
 - **Apathy** – lack of motivation and of interest in once important things
 - **Lack of empathy** – inability to put oneself in another's shoes
 - **Anxiety, panic attacks, phobias** – mood disorders leading to worry, tiredness, irritability, or fears of such things as the dark, being left alone, crowds, bathing; may lead to inappropriate behaviors
 - **Agitation** – increased tension and irritability resulting in inappropriate, possibly aggressive behaviors

Behavioral and Mood Changes

- **Sleep disorders** – LBD interferes with the ability to get the sleep needed to restore and rejuvenate brain function.
 - ***Insomnia*** – difficulty falling and/or staying asleep; may wake up often during the night and have problems going back to sleep
 - ***REM sleep behavior disorder (RBD)*** – acting out dreams while asleep by talking, laughing, shouting, gesturing, grabbing, flailing arms, punching, kicking, sitting up or leaping out of bed
 - ***Apnea*** – “forgetting” to breathe during sleep for multiple short periods
 - ***Excessive daytime sleeping*** – napping for long periods even with good nighttime sleeping

Behavioral and Mood Changes

- **Disinhibition** — impulsive and inappropriate behavior, with little insight or judgment; can be hurtful to others; may be sexual or self-destructive
- **Shadowing** — following or repeatedly checking on location of spouse or caregiver
- **Wandering** — wandering off from others, leaving the house unaccompanied, walking aimlessly, night-time wandering
- **Catastrophic reactions** — extreme and sudden emotional reactions that are expressed with physical and/or verbal outbursts that seem inappropriate or out of proportion to the situation

Behavioral and Mood Changes

- **Inappropriate behaviors –**

- *Physically non-aggressive behaviors* such as restlessness, pacing, hiding things
- *Verbally non-aggressive behaviors* such as negativism, repetition, interruptions
- *Physically aggressive behaviors* such as hitting, pushing, scratching, kicking, biting
- *Verbally aggressive behaviors* such as threatening, cursing, making strange noises

Behavioral and Mood Changes

What's your story?



Causes and Triggers

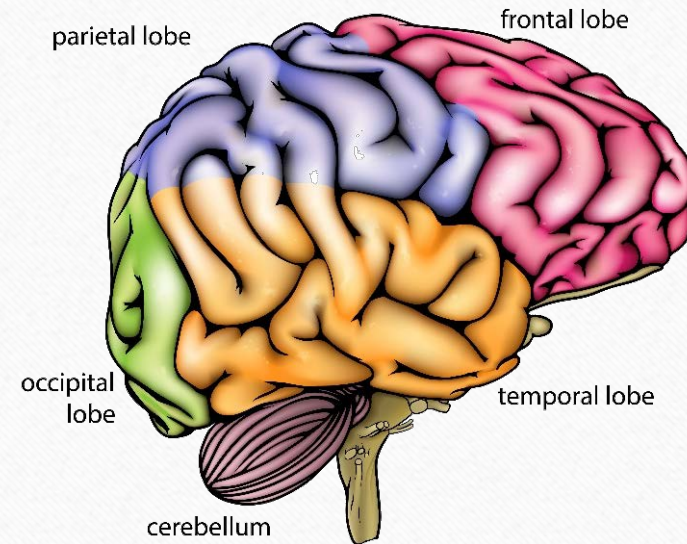
- A stressor; a stressful irritant
 - physical or health issues
 - environmental influences
 - types of social interaction and communication
- A way for your loved one to communicate needs and concerns
- A direct result of the changes in the brain from the disease itself

Causes and Triggers

Lewy bodies in the brain

Alpha-synuclein protein clumps together

- causing the neurons to weaken and die.
- affecting brains chemicals – neurotransmitters that activate brain functions.
- Symptoms depend on
 - the number of Lewy bodies.
 - where the Lewy bodies are in the brain.



Causes and Triggers

Health issues

- Extreme tiredness, fatigue
- Sleep disorders
- Physical discomfort, pain
- Fever, infections
- Loss of autonomic functioning
- Parkinsonism - movement problems
- Problems with vision or hearing
- Medication side effects



Causes and Triggers

Social interaction and communication

- Inability to understand
- Need to feel understood
- Sense of loss
- Fear
- Need for attention
- Reaction to negativity
- Grief
- Responses to hallucinations and delusions



Causes and Triggers

Environmental factors – the physical environment or task demands

- Lighting – too dim; not enough visual contrast; too bright, painful to eyes
- Noises, voices, sounds: loud, unpleasant, sudden, competing, or persistent
- Temperature too hot or too cold
- Unsafe environment (actual or perceived)
- Objects that can be misinterpreted (mirrors, drapes, coat stands, art work, etc.)
- A sudden change in environment (including a visit to the ER, hospitalization, transfer to a rehabilitation facility, a vacation, or move to a new home or long term care facility)

Causes and Triggers

- Uncomfortable clothing
- Over-stimulation or under-stimulation
- Expectations too high or too low
- A traumatic or distressing incident
- Too many people in the immediate area or social isolation or lack of social support
- Rough, abrupt, insensitive physical handling

Causes and Triggers

To the extent possible, include your loved one in identifying triggers.

Causes and Triggers



Are you a good detective?

Non-drug Strategies to Prevent/Curb Behaviors

Care partners can incorporate evidence-based, non-drug strategies into daily life.

- may possibly prevent behavioral changes
- may help curb challenging behaviors
- are informed, person-centered, empathetic, and accepting
- are part of *responsive dementia care*

Non-drug Strategies to Prevent/Curb Behaviors



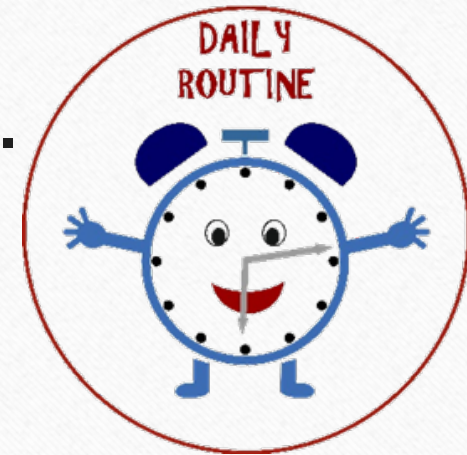
Closely monitor the person's physical health.

Create a safe and comfortable home environment.



Non-drug Strategies to Prevent/Curb Behaviors

Establish and maintain a daily routine.



Make sure your loved one gets enough sleep.

Non-drug Strategies to Prevent/Curb Behaviors

Provide sufficient healthy and attractive food.



Be sure that your loved one stays hydrated.

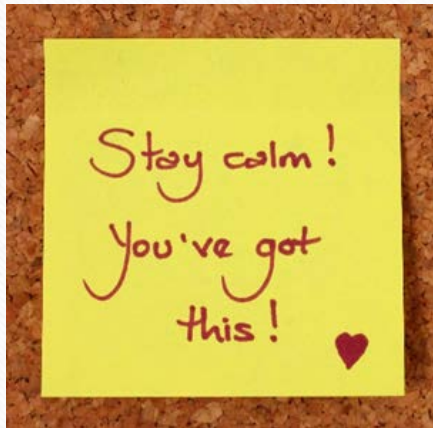
Non-drug Strategies to Prevent/Curb Behaviors

Make bathing/hygiene activities pleasant, safe, and calm.



Avoid media with potentially disturbing content.

Non-drug Strategies to Prevent/Curb Behaviors



Communicate positively in a calm reassuring voice.

Engage your loved one in enjoyable meaningful activities.



Non-drug Strategies to Prevent/Curb Behaviors

Identify people who trigger behavioral changes.



Incorporate one or more of the non-drug therapies.

Non-drug Strategies to Prevent/Curb Behaviors

What works for you?

You'll
NEVER
Know
TILL YOU'VE
Tried

Non-drug Strategies to Manage Behaviors

LBD experts recommend non-drug approaches as the first line of treatment.

- to manage, reduce, or perhaps even eliminate many challenging behaviors
- often as or more effective than drugs
- avoid the adverse effects of many drugs
- may take several attempts to find the best strategies

Non-drug Strategies to Manage Behaviors

Responsive care: A four-step process

- **Knowledge** —
Understanding how dementia changes the brain
- **Acceptance** —
Putting your own reality on hold and accepting theirs
- **Empathy** —
Imagining how you'd feel in their situation
- **Action** —
Being responsive, supportive, and person-centered.



Non-drug Strategies to Manage Behaviors

Use a problem solving approach such as DICE.



- **D**escribe the details of the behavior: who, what, when, and where.
- **I**nvestigate the causes of the behavior.
- **C**reate a plan to respond to behavioral issues.
- **E**valuate the outcome and changes needed.

Non-drug Strategies to Manage Behaviors

Don't take any behavior personally. It's Lewy not your loved one!

- Don't argue; agree and validate your loved one's feelings.
- Don't reason; accept your loved one's reality.
- Don't defend; apologize. Yes! apologize. It works.
- Don't correct; go with the flow.



Non-drug Strategies to Manage Behaviors

- Redirect and distract; offer an enjoyable activity.
- Use touch; gentle physical contact calms.
- Stay positive; negative emotions block communication.
- Take a time out; leave the room and come back later.
- Stay calm; carry on.

Non-drug Strategies to Manage Behaviors

Only use strategies that maintain your loved one's personhood with dignity and respect.



Non-drug Strategies to Manage Behaviors

Use “therapeutic fibbing.”

- With dementia, comfort and peace are more important than honesty.
- Respond from your loved one's reality.
- Use words that don't worry or agitate - even if they aren't quite true.
- Then use distraction or deflection. "Tell me about...." For example, if a person wants to go home, say, "Let's eat dinner first" and "Tell me about your home."

Non-drug Strategies to Manage Behaviors

OR be an improv actor.

- Accept their reality and flow with it.
- Listen with an open mind; respond to emotions more than words.
- Agree verbally or non-verbally and accept your given role.
- Stay in the moment, in the here and now.
- Make contributions that slowly move the action towards your goal without conflict.
- Use invitations, which include; not directives, which divide.
- Give yourself permission to fail.

Non-drug Strategies to Manage Behaviors

Consult with your loved one's health care team.

Don't try to do everything yourself.

Non-drug Strategies to Manage Behaviors

Are you ready to...



Alternative Non-drug Therapies

- Are used in combination with traditional medicine.
- Often lead to the need for fewer drugs and a better quality of life.
- Are safer and often more effective than many drug treatments.
- Are person-centered with the focus on treating the whole person.
- Make the person more comfortable and decrease stress and pain.



Alternative Non-drug Therapies

Physical therapy	General physical fitness
Occupational therapy	Speech therapy
Art therapy	Music therapy
Aromatherapy	Light therapy

Alternative Non-drug Therapies

Reminiscence therapy	Massage therapy
Pet therapy	Nutrition therapy
Light therapy	Validation therapy
Support groups	Individual and Family therapy

Alternative Non-drug Therapies

Which do you want to use?



Learn how to use each of the therapies and their benefits at
www.lbdtools.com/events.php

See www.lbdtools.com/events.php

- Presentation abstract
- Presenters' LBD background
- Presentation poster
- Presentation slide deck
- Additional care partner resources on each topic

For More Information about LBD

www.lbda.org

www.lbdtools.com

www.lewybodydementia.ca

<https://lewybodyresourcecenter.org>

For Support

Face-to-face LBDA-sponsored support groups:

See https://www.lbda.org/lbd-local-support-groups?field_state_value=AK

Online support group for spouses of people living with LBD:

<https://groups.io/g/LBDCaringSpouses>

LBDA-sponsored online support group for people living with LBD:

<https://www.facebook.com/groups/LBDALivingwithLewy/>

LBDA-sponsored online support group for care partners of people living with LBD:

<https://www.facebook.com/groups/LBDACarePartnerSupportGroup/>

LBDA-sponsored online support group for people living with LBD and their care partners who are newly diagnosed with LBD and those who have early symptoms of LBD:

https://www.facebook.com/groups/LBDALivingTogetherwithLewy/?hc_location=group

To Use These Materials

LBD support group facilitators and others who provide educational and awareness activities may use these materials.

- Please do not modify them.
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