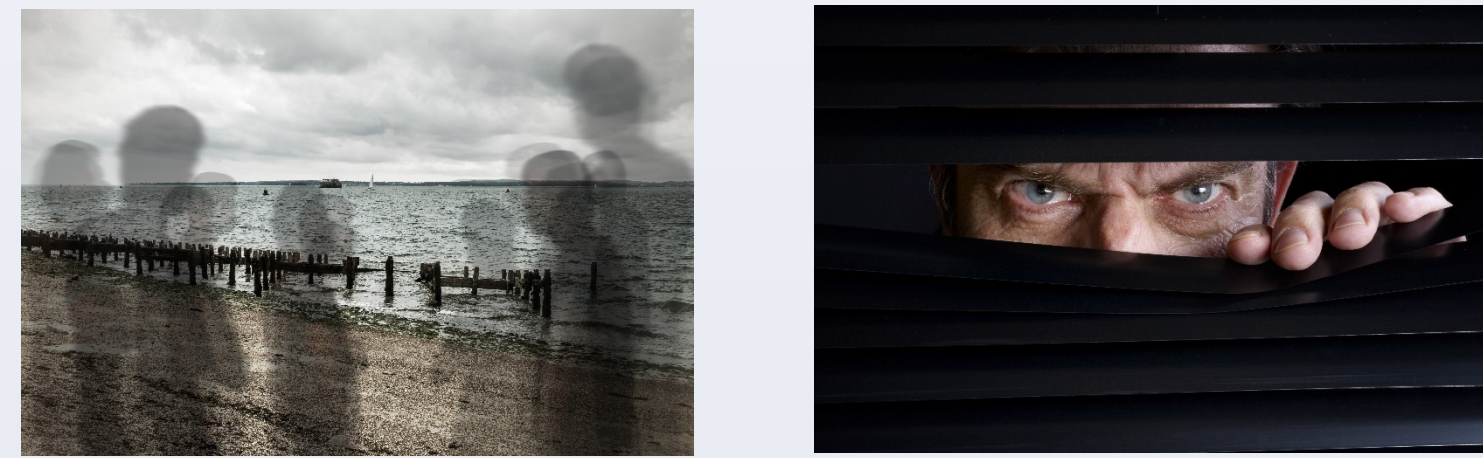


Non-drug Approaches for Care Partners to Use When a Loved One Living with LBD has Behavioral Changes

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Behavioral and Mood Changes

- 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



- **Visual hallucinations** — clearly seeing something that isn't there, often with great detail
- **Auditory hallucinations** — false perceptions of sound such as buzzing, knocking, background music, or people speaking
- **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
- **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 - **Capgras syndrome** — a delusional belief that a person - often a spouse, other close relative, or a friend - has been replaced by an identical double or imposter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
- **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
- **Disinhibition** — impulsive and inappropriate behavior, with little insight or judgment; can be hurtful to others; may be sexual or self-destructive.
- **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
- **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
- **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

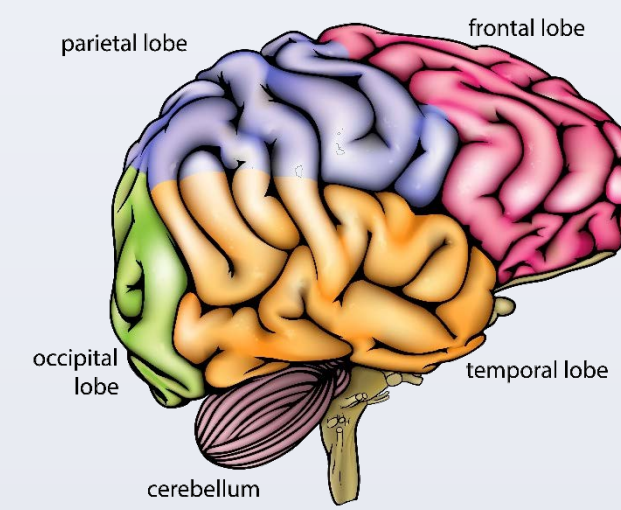
What's your story?

Causes and Triggers

- A direct result of the changes in the brain from the disease itself
- 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

Lewy bodies in the brain

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



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



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



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)
- 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

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



Are you a good detective?

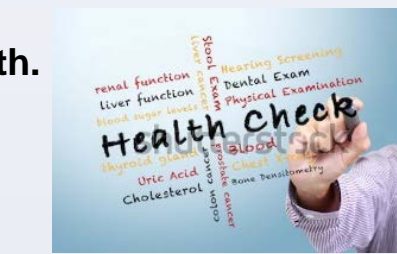
Non-drug Strategies to Prevent/Curb Behaviors

- 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*

Closely monitor the person's physical health.



Create a safe and comfortable home environment.



Establish and maintain a daily routine.



Make sure your loved one gets enough sleep.

Provide sufficient healthy and attractive food.



Be sure that your loved one stays hydrated.

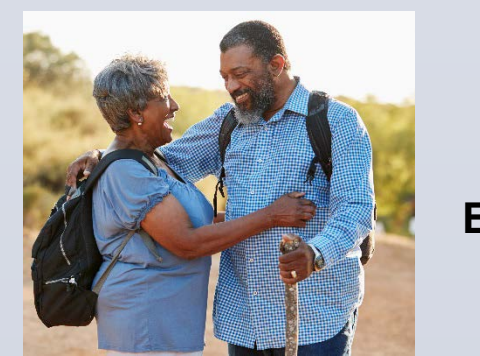
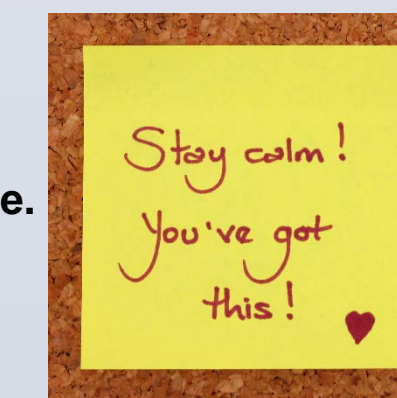


Make bathing/hygiene activities pleasant, safe, and calm.

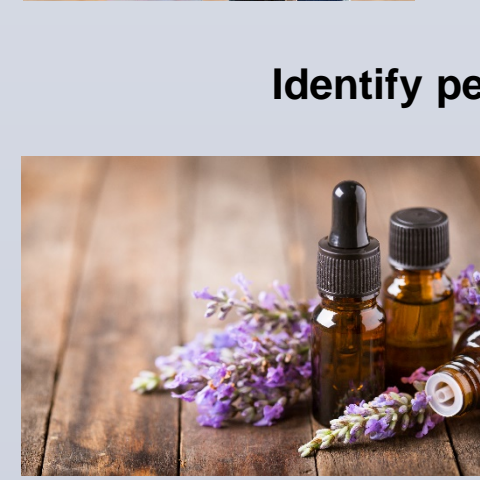


Avoid media with potentially disturbing content.

Communicate positively in a calm reassuring voice.



Engage your loved one in enjoyable meaningful activities.



Identify people who trigger behavioral changes.



Incorporate one or more of the non-drug therapies.

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

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.



Use a problem solving approach such as DICE.

- Describe the details of the behavior: who, what, when, and where.
- Investigate the causes of the behavior.
- Create a plan to respond to behavioral issues.
- Evaluate the outcome and changes needed.



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.
- 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.



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



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."

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.

Consult with your loved one's health care team. Don't try to do everything yourself.

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.



Physical therapy	General physical fitness
Occupational therapy	Speech therapy
Art therapy	Music therapy
Aromatherapy	Touch therapy
Reminiscence therapy	Massage therapy
Pet therapy	Nutrition therapy
Light therapy	Validation therapy
Support groups	Individual and family therapy

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

Which do you want to use?

