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# DEMENTIA WITH LEWY BODIES INTERVENTIONS

## Suggestions for
## Helping a Person Living with DLB

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## TO KEEP IN MIND

1. Please see **CAIS Handout** "**#20 Dementia with Lewy Bodies**: Information and Intervention Suggestions with an Emphasis on Cognition". It has more details, examples, and information regarding Dementia with Lewy Bodies (DLB), including characteristics, neuropathology, location of brain changes, cognitive changes, emotional changes, behavioral changes, cognitive and other nonmedical interventions, medical treatments, and resources.
2. Also, please see **CAIS Handout** "**#29 Visual-Spatial Interventions**: Suggestions for Helping a Person by Addressing their Visuospatial Abilities", and other CAIS **Handouts** about interventions including, for example, **#27** about **touch**, **#28** about **movement**, and **#34** about **sleep**.
3. More details and specific interventions are also available in the *Cognitive Abilities and Intervention Strategies (CAIS): Questions to Ask* and ***CAIS**: **Intervention Strategies*** by S. Weaverdyck. For example, see the **Cognitive** Intervention Strategies part (sections **II-Perception** and **IV Expressive** Functions) and the **Environmental** Intervention Strategies part. The ***CAIS*** provides **detailed intervention** strategies that address specific cognitive abilities, the environment, tasks and daily routines, and your communication with this person. These interventions can be **individualized** to a particular person and situation.
4. All of these **CAIS Handouts**, the **CAIS Questions** and **Interventions**, and other **resources** are on the Improving MI Practices website at **https://www.improvingmipractices.org**
5. See the website for the Lewy Body Dementia Association at **https://www.lbda.org**
6. All of these interventions include **support strategies**.
7. Abbreviations are **DLB** for Dementia with Lewy Bodies, and **AD** for Alzheimer's Disease.

## DEMENTIA WITH LEWY BODIES

8. A person living with DLB (a type of Lewy Body Dementia) may experience various symptoms, such as **Parkinsonian symptoms** (for example, slowness in movement, rigidity, difficulty initiating movement), **falls** (due to syncope or reduced balance and muscle control), **sleep disturbance** (including trouble sleeping, vivid night-time dreams, and acting out dreams), and **visual hallucinations** (that might feel real and also feel unreal). (A visual hallucination is something a person sees but no one else sees and is not real.) There may also be **episodes** of **unresponsiveness**, **sensitivity** to **neuroleptic medications**, and various **cognitive changes** including **visuospatial difficulties**, **misinterpretation** of another person's intentions or motives, and **hypersensitivity** to **noises**. **Unpredictability** is common due to **fluctuations** in mood or emotions, cognitive abilities, and **ability** to **perform tasks** over minutes, hours, days, weeks, or longer periods of time. For example, they may have "good" days and "bad" days.
9. Sometimes family, care partners or caregivers, and others doubt this person really has dementia since it can look different from AD which is more common. For example, compared to a person living with AD, a person with DLB may be able to **remember more details** and be more logical. They may be

able to more easily argue or **rationalize** a false belief. They may also have more **difficulty performing tasks** including self-care and other daily tasks (such as **activities of daily living**, ADLs**)**, even though they seem to be able to do other complex tasks and talk about complex topics.

10. Families, care partners or caregivers, and others may need significant **education** and **reassurance** due to this person's unpredictability and sudden changes in moods and abilities. They may feel this person is manipulative and sometimes pretending they can't do a task. They may feel exhausted by this person's sudden striking out without apparent warning. They may be less confident in their own perception due to the unpredictability and fluctuations throughout the course of DLB. They may feel guilty if this person is quite verbal and can logically argue against the family's decisions. They may not trust their own decisions. Family members who live at a distance, may not understand how this person has changed, since this person may "rise to the occasion" when these family members visit and appear more able than they often are. Similarly, physicians and other health professionals may see this person when they are able to talk logically and appear less confused or emotionally distressed, since again this person may be able to "rise to the occasion". Since this person may not be able to maintain this higher level of functioning for a sustained period of time, the family may assume this person is being manipulative.

## SOME INTERVENTION SUGGESTIONS

11. Learn and share information about DLB with this person, family, and others. (Be alert to timing and readiness to understand and receive information. See **CAIS Handout** "**#39 Sharing Ideas and Information** with Others".) Include, for example:
    a. A description of the **course** of DLB: noting its unpredictability and fluctuations.
    b. A suggestion to remember it is **dementia** even when this person appears unlike a person with AD (as described above).
    c. The **fluctuations** in mood, ability to think, or ability to perform tasks ("good" days and "bad" days).
    d. A caution that some days **expectations** can be too high (thinking this person needs **less** help than they do) or too low (thinking this person needs **more** help than they do). Surprise, suspicion, **frustration**, and **resistance** can result.
    e. The **unpredictable** nature of this person's behavior, cognition, and ability to do tasks.
    f. How easy it is for all involved to **feel guilty**.
    g. Encourage this person, family, and others to be in a **problem-solving** way of thinking from early on so they can continue it more easily throughout the course.
12. **Reassure** yourself, this person, family, and others. (Address frustration, fatigue, uncertainty, sense of guilt, anger, doubt about their own perceptions.)
    a. Address emotions.
    b. Continue to support them throughout the course (show them they are not alone).
    c. This person may need to move to a long-term care setting earlier than in AD (perhaps due to family fatigue, uncertainty, or distress).
13. **Be cautious with medications**, particularly neuroleptics. A neuroleptic might address hallucinations and other symptoms, but may make the Parkinsonian symptoms worse. Treating the Parkinsonian symptoms (such as rigidity and slow movement) may make the hallucinations and other symptoms worse. Medications need to be constantly monitored and adjusted as this person changes.
14. **Protect** the **sleep partner** and **others** nearby, as well as **this person**. This person may act out a dream and physically hurt someone near them or themselves without realizing it. Since this usually happens at night, others may not understand that this is occurring.
15. **Avoid stress** and **demands** on **"bad" days** (for example, do difficult tasks such as bathing on "good" days).
16. **Assist with ADLs** (Don't assume this person "can do it if they wanted to").
17. **Exercise muscles and joints**.

    a. Walk to keep legs from going numb and to reduce rigidity.
    b. Exercise the upper body.
    c. Maintain range of motion in joints.

18. **Reduce sound in the environment.** Keep the space quiet and sounds recognizable and predictable to this person, especially if they are hypersensitive to noise. Unexpected sound, such as a fan turning on or a door closing, can cause this person significant discomfort or even pain, and can cause them to strike out suddenly.
19. **Use visuospatial interventions** (see CAIS Handout "**#29 Visual-Spatial Interventions**").
    a. **Environment**:
        - **Structure this person's space** and **keep it consistent** (avoid changes).
        - For example, reduce clutter and patterns, increase contrast, keep location of objects consistent)
    b. **Communication and interactions**:
        - Use economy of movement (for example, move minimally, gesture minimally and meaningfully).
        - Organize the task so most of your movement is out of sight of this person.
        - Watch for this person's reaction and adjust your response.
        - Slow down, pause, and move slowly.
        - Approach this person from the **front** and stay in the strong part of their visual field.
20. **Adapt** your **touch** if this person is **hypersensitive** to touch (See CAIS Handout "**#27 Touch**").
    a. Adjust their clothing.
    b. Avoid skin contact with water and moving air. For example, cover the faucet or shower nozzle with a cloth, or cover their skin with a towel to protect from the spray of water from a faucet or shower nozzle.
21. **Avoid arguing** with or **"correcting"** this person.
22. **Hallucinations:**
    a. **Ask** this person **carefully** (maybe indirectly) about hallucinations. This person may be worried about the hallucinations if they sense they are not real, and may not want to tell you about them.
    b. **Explain** hallucinations are likely part of the DLB and that this person is not "going crazy".
    c. **Ask** them if they sometimes know or think maybe a hallucination **isn't real**.
    d. **Discuss** with this person, if possible, how they feel about their hallucinations and what you can do to help them during a hallucination and in general.
    e. Consider ways to tactfully explore a hallucination and show it isn't real when necessary.
    f. **Plan with this person** how, when in public, someone might give them subtle cues that a hallucination isn't real.
    g. Help this person plan to use **reality checks** during a hallucination. Suggest they, for example:
        - Watch the reactions of other people present.
        - Ask other people present about it (for example, ask if others also see it).
        - Try to touch, hear, or smell it.
        - Wait to see if it disappears or changes.
        - Analyze it for the likelihood it is real.
    h. **When they occur**, respond in a way you and this person have agreed upon during an earlier discussion, if a discussion was possible. For example:
        - Remain calm and watch this person.
        - Interact with this person if that is helpful.
        - Avoid saying during a hallucination that it isn't real and isn't occurring, unless you agreed during an earlier discussion with them to do so.
        - Ignore it when that seems appropriate, particularly if the hallucination is not

  distressing or is even comforting.
  - **Address** this person's **feelings** and **reassure** this person verbally and nonverbally. For example, tell them you don't see what they see, but that you see they are upset and you want to help them.
  - Ask what they would like you to do to be helpful.
  - Suggest what you could do, for example, ask if they would like you to try to remove the bugs on the wall, or swipe the wall and ask if that helped.
  - Help this person move to a different place or turn them so they face a different direction, in case what they see is a misinterpretation of reality (for example, an object in front of them looks frightening because they think it is something it isn't).
  - Participate in the hallucination if it is an elaborate scenario until they tell you it is over. For example, if they hand you a mop as a weapon for when the "enemy" comes, then hold the mop until the scene is over.
  - Keep this person, other people, and yourself safe throughout the hallucination.

23. Maintain **flexible** and **accurate expectations** of this person (expect fluctuations).
24. **Address** the **unpredictability** of cognition, emotions, and behavior (for example, be prepared with interventions).
25. **Support this person** by **listening**, sharing **information**, and **exploring strategies** with them **from early on using their insight**, problem solving skills, and habits that may stay intact well into the course of their DLB.
26. **Prevent falls** (for example, exercise, modify the space to avoid hazards, assist this person during movement, use equipment for assistance when helpful).
27. **Soften** the environment to reduce risk of injury from falls.
28. Monitor **night-time sleeping** behavior and alter sleeping arrangements as necessary. Keep a journal. (See **CAIS Handout #34** about **sleep** interventions.)
29. Monitor for mood shifts, **triggers**, and unexpected behavior that can be or look like aggression.
30. **Respond immediately** by adapting the **environment**, your **communication**, or the **task** to accommodate this person's experience or changes in abilities.
31. Have someone be with this person at all times (or at key times), if necessary, to prevent unpredictable behavior that can be or look like aggression.
32. **Treat depression**. Depression can be common with DLB.
33. **Address pain** immediately and consistently (for example, be gentle, ask permission to move a part of this person's body, go slowly). (See **CAIS Handout #28** about **movement**.)
34. If this person becomes anxious or resists walking through **doorways** or entering **small rooms** such as bathrooms, walk slowly ahead of them facing them (so you are walking backwards), hold their hands or walker, talk with them to slightly distract them, and have them focus their attention on your face as you walk with them through the door or into the room.
35. Avoid embarrassing this person. Use interventions discreetly to **save face**.
36. **Adapt** interventions to this person as an **individual**.
37. **Adapt** interventions as the **DLB progresses**, as this **person changes over time**, and as **circumstances** change.
38. Identify the **compensation strategies this person uses** consciously and unconsciously and build on them.
39. For intervention and treatment for physical or medical challenges see **CAIS Handout #20** about **DLB**.
40. Remember what you **like** and **admire** about this person.