DEMENTIA WITH LEWY BODIES INTERVENTIONS

Suggestions for Helping Someone with Dementia with Lewy Bodies

Shelly Weaverdyck

TO KEEP IN MIND

1. Please see the handout "**Caring Sheet #12: Dementia with Lewy Bodies: A Summary of Information and Intervention Suggestions with an Emphasis on Cognition**" by Shelly Weaverdyck. It has much more information regarding Dementia with Lewy Bodies (DLB), including characteristics, neuropathology, location of brain changes, cognitive changes, emotional changes, behavioral changes, non-pharmacological interventions, medical treatments, and resources.
2. Also, please see the handout "**Visual-Spatial Interventions: Suggestions for Helping Someone with Impairment in Visuospatial Functioning**" by Shelly Weaverdyck.
3. A person with DLB may experience **Parkinsonian symptoms**, **falls** (due to syncope or reduced balance and muscle control), **visual hallucinations** (that might feel real and also unreal), and **sleep disturbance** (including trouble sleeping, vivid night-time dreams, and acting out dreams). There may also be along with the cognitive impairment, **visuospatial impairment**, misinterpretation of another person's intentions or motives, **episodes of nonresponsiveness**, **hypersensitivity to noise**, and **sensitivity to neuroleptic medications**. **Unpredictability** is common due to **fluctuations** in mood or emotions, cognitive abilities, and functional abilities over minutes, hours, days or longer periods of time. For example, they may have good days and bad days.
4. Sometimes family and other carers doubt this person really has dementia since it can look different from Alzheimer's Disease (AD) which is more common. For example, compared to a person with AD, a person with DLB may be able to **remember more details** and be more logical. They may be more able to argue or rationalize a false belief. They may also be more **impaired in activities of daily living (ADLs)**, even though they appear high functioning enough to be able to perform tasks.
5. Families and other carers may need significant education and reassurance due to the person's unpredictability and sudden changes in moods and abilities. They may feel the person is manipulative. They may feel exhausted by the person's sudden striking out without apparent warning. They may be less confident in their own perception due to the unpredictability and fluctuations in the course of DLB. They may feel guilty if the person is quite verbal and can logically argue against the family's decisions.

SOME INTERVENTION SUGGESTIONS

6. **Educate the person and family/carers** (Be alert to timing and their receptivity)
   Tell them about DLB including:
   a. A description of the course of DLB: noting its unpredictability and fluctuations
   b. To remember it is dementia even when the person appears normal or unlike a person with AD (e.g., their memory for details or ability to argue)
   c. The fluctuations in mood, ability to think, or ability to perform tasks (good days and bad days)
   d. A caution that expectations can be too high (or too low) some days
   e. The unpredictable nature of the person's behavior, cognition, and level of functioning
   f. How easy it is to feel guilty

7. **Reassure the person and family/carers** (The person and family may feel more angry and guilty than in AD. They may doubt their own perceptions, doubt it is dementia, be frustrated, be exhausted)
    a. Address the family's and person's emotions, uncertainty, frustration, and sense of guilt
    b. Continue to support them throughout the course (show them they are not alone)
    c. The person may need to move to a long-term care setting earlier than in AD (perhaps due to family fatigue, the family is unclear in their perception, or the family feels distress)
8. **Be cautious with medications**, particularly neuroleptics
9. **Protect the sleep partner and others near by**
10. **Avoid stress and demands on "bad" days** (e.g., do difficult tasks such as bathing on "good" days)
11. **Assist with ADLs** (Don't assume this person "can do it if they wanted to")
12. **Exercise muscles and joints**
    a. Walk to keep legs from going numb and to reduce rigidity
    b. Exercise the upper body
13. **Reduce sound in the environment.** Keep the space quiet and sounds recognizable and predictable.
14. **Use visuospatial interventions** (please see the handout identified above in #2)
    a. **Environment:**
        Structure space and keep it consistent (avoid changes)
        (e.g., reduce clutter and patterns, increase contrast, keep location of objects consistent)
    b. **Carer interactions:**
        Use economy of movement (e.g., move minimally, gesture minimally and meaningfully)
        Organize the task so most of the carer movement is out of sight of this person
        Watch for this person's reaction and adjust the carer's response
        Slow down, pause, and move slowly
        Approach this person from the front and stay in the strong part of their visual field
15. **Adapt your touch if this person is hypersensitive to touch** (See the handout "Touch" by S Weaverdyck)
16. **Avoid arguing or "correcting" the person**
17. **For Hallucination:** explain, reassure, give subtle cues in public, don't deny it's there, maybe ignore it
    a. Ask carefully (maybe indirectly) about hallucinations
    b. Help carers find ways to tactfully explore a hallucination and show it isn't true if necessary
    c. Help person with reality checks: Watch or ask others about it; Try to touch, hear, smell it; Wait to see if it disappears or changes; Analyze it for likelihood;
18. Maintain flexible and **accurate expectations** of person (expect fluctuations)
19. **Address unpredictability** of cognition, emotions, and behaviors (e.g., be prepared with interventions)
20. **Counsel person from early on using their insight**, problem solving skills, habits that may stay intact
21. **Prevent falls** (e.g., exercise, modify the space, assist the person during movement, use equipment)
    a. Soften the environment to reduce risk of injury from falls
22. Monitor nighttime sleeping behavior
23. Monitor for mood shifts, **triggers**, and unexpected behaviors that can look like aggression
24. Use 1:1 companionship if necessary to prevent unpredictable behaviors that can look like aggression
25. Treat depression
26. **Address pain**
27. Avoid embarrassing this person. Use interventions discreetly to save face.
28. Remember what is lovable about this person