



ECHO Idaho: Alzheimer's Disease and Related Dementias CASE RECOMMENDATION FORM

ECHO Session Date: 10/22/2024

Presenter Credential: LCSW, GMHS

Thank you for presenting your patient at ECHO Idaho –Alzheimer’s Disease and Related Dementias session.

Summary:

The case presentation I am providing involves a couple, as is frequently the case with my practice. The primary client is the 70-year-old wife/caretaker of her husband who is 72 years old. He has been diagnosed with Alzheimer’s type dementia for 4 years confirmed with imaging and followed by a neurologist for twice yearly checkups. He has never been on any of the medications to help slow the progression of the disease because he has a pacemaker, and they are contraindicated due to that reason.

Question:

- Concern for caregiver burnout specifically how she can extricate herself and trust that he will be in good hands. They do have financial resources for this and adult children but she has great difficulty leaving him.
- Ideas on how to encourage spouse/caregiver to feel more comfortable in letting friends know what is happening (currently isolating from their friends out of respect to her husband not wanting to reveal the truth or show how it has progressed).
- Specific interest in hearing from occupational therapy regarding home safety eval and ideas for ways he can engage in tasks he can feel successful with around the house.
- Safety concerns regarding wandering, eating or drinking something causing harm (recent incident).
- Sensory loss of vision in one eye and hearing for husband (he did just get new hearing aids but he still has trouble).

Thank you so much for presenting. And I'm so grateful they have you to support them.

After review of the case presentation and discussion of this patient’s case among the ECHO Community of Practice, the following suggestions have been made:

RECOMMENDATIONS:

Balancing Care and Autonomy:

- Continue discussing the importance of balancing priorities when creating advanced directives.
- The main focus seems to be ensuring that care decisions are sustainable and meet the person's needs, while respecting their autonomy and dignity. However, if keeping someone at home compromises their well-being



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or quality of life, the situation needs reevaluation. Each meeting/session needs to involve discussing these evolving needs and ensuring that decisions remain aligned with the individual's preferences and best interests.

Introducing Caregivers:

- Encourage the caregiver to think ahead about the future need for professional caregiving, rather than focusing solely on the current situation. While she may not need help today, exploring what it would look like if a professional caregiver was needed can help prepare for the transition.

Social Support and Stigma:

- Dementia is often seen as an 'invisible disease' at the early stages, but as it progresses, friends often pick up on the fact that something is wrong. Therefore, the wife's concern to 'not tell' friends may be a moot point already.
- The caregiver may feel embarrassed and unsure of how to handle her partner's condition in social settings. A discreet way to inform friends is through resources like the Alzheimer's Association, which offers a business card ([Alzheimer's Association Companion Card](#)) that subtly explains the situation without needing to discuss it directly.
- Instead of immediately hiring a caregiver, a helpful approach could be asking a trusted friend to spend time with the loved one—going for a walk or a drive—allowing the caregiver some respite without feeling like they're handing over control to a stranger.

Home Safety and Engagement:

- It's crucial to balance safety, autonomy, and dignity when caregiving, especially when the caregiver is withdrawing from social situations to hide a loved one's illness. This may stem from a desire to protect the person's dignity, even if it wasn't explicitly expressed by the individual with the illness.
- Work with an Occupational Therapist for the following:
 - Complete a basic home safety assessment.
 - An OT would look for environmental barriers to safety and make recommendations to move furniture, remove rugs, add grab bars, etc. if needed. An OT would also look at items around the house that are at knee height and below. As a person progresses through the stages of dementia, the person does not attend to things outside of their immediate visual area and issues with visual perception/visual spatial skills become a factor.
 - Review of potentially dangerous items such as sharps, alcohol, and other items in the home that could be dangerous to the PLWD.
 - Complete an occupational profile to determine the person's occupational history, habits, routines and past interests to tailor to the PLWD. This also would help when assisting the caregiver to find activities/tasks that the PLWD can do successfully and safely that are meaningful to them.
 - Educate the caregiver/s in how to provide encouragement and cues to help them continue to engage and step in when frustration might cause negative behavior.
 - Wandering/eloping is common and the OT could make suggestions on how to distract the PLWD from the door by using signs (stop sign) or decorate the door to camouflage it.
 - OT can work with individuals in home health if they are deemed "homebound." Medicare Part B covers outpatient therapy, allowing OT services in the home, which is ideal for those with dementia.
 - Intimacy, including sexual relationships, may change with dementia. OTs can guide caregivers on how to maintain closeness through non-sexual forms of intimacy, like holding hands, giving massages, or taking walks, while addressing concerns about consent and changing sexual behaviors. One helpful option that helps address intimacy and hygiene needs is to shower together.



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Medication Use:

- Based on the current situation, no medication changes are recommended.
- We advise against using sedatives to manage behaviors like mischief or restlessness in dementia patients, as they often cause more problems, such as falls, confusion, or agitation. Instead, environmental changes should be prioritized to ensure safety.
- Medications might be considered only in truly dangerous situations, like wandering at night, but the goal should be to remove them once the environment is secure.

Caregiver Health:

- Dementia caregivers face a high risk of burnout and health decline, with studies showing up to 40% of them may die before their care recipients.
- It could be helpful to ensure that adult children are made aware of this risk to encourage more help.

Using Technology for Safety:

- Secure items in the home that could pose risks at night, such as alcohol, snacks, or the stove, by locking them away or using stove locks and safer appliances like convection ovens.
- Utilize technology like temperature alarms, gun locks, and hidden car keys to enhance safety, and consider involving tech-savvy family members or professionals if resources are available
- Keeping the individual active during the day and exposing them to natural light in the morning and evening can also improve sleep by supporting their circadian rhythm.
- Consider freezer alarms that sound when temperature drops below a certain point to prevent from losing years' worth of food in a moment of forgetfulness.

Trusting Outside Help:

- For caregivers hesitant to bring someone into the home, consider piloting a caregiver on a trial basis to test the arrangement. This approach can help the caregiver and the individual adjust gradually, avoiding the shock of abruptly introducing a caregiver for extended period.
- Consider having the caregiver stay present during the first few visits. This allows the patient to adjust gradually by doing activities together with the caregiver and the loved one, creating a warm and slow transition where the caregiver takes over gradually.
- If the patient or spouse resists allowing a caregiver, sometimes adult children can step in and make the decision to hire someone. Starting with everyone present—parents, children, and the caregiver—can help ease the transition, with the family slowly stepping back until the hired caregiver is the primary support.

Resources:

[Alzheimer's Association Companion Card](#)

[Idaho Community Care Program](#) (statewide caregiver support)

Idaho Commission on Aging : [A Workbook for Family Caregiver -- Navigating Dementia \(Idaho\)](#)

Book: [Travelers to Unimaginable Lands: Stories of Dementia, the Caregiver and the Human Brain](#)

Book: [Dementia Home Care: How to Prepare Before, During, and After](#)

Book: [Creative Care: A Revolutionary Approach to Dementia and Elder Care](#)

[Well Spouse Association](#)