



Alzheimer's Awareness Family Night

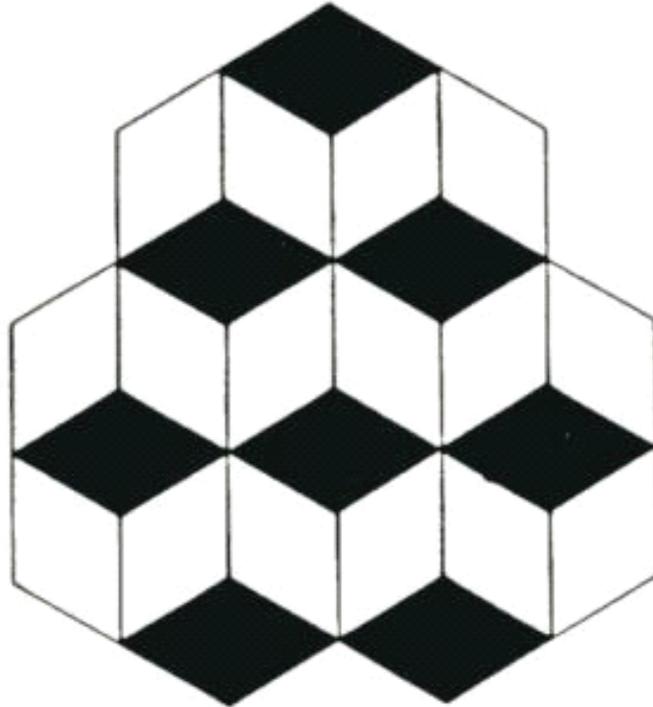
HANDOUTS AND RESOURCES

SESSION #3:

What motivates the actions of a person with Alzheimer's disease?

Handout #1: Opening Exercise

Look at the figure below. Do the black diamonds represent the tops of the cubes or the bottoms? Is there more than one way of looking at it? This figure is intended to remind you that the way you view a situation may be different from the way the person with Alzheimer's disease views it. One is not necessarily more "right" than the other.



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Handout #2: No-Pressure Quiz

Please answer each question to the best of your ability OR leave your quiz paper blank, and fill in the correct answers during our group discussion.

1. **Which of the following statements about fatigue in people with AD is NOT true?**
 - a. It may be related to physical illness.
 - b. It is usually more of a problem in the morning.
 - c. It can cause irritability.
 - d. It interferes with the person's ability to think clearly.
 - e. People with AD tend to tire more easily and more often as their disease progresses.

2. **Which of the following is LEAST likely to be frustrating to a person with AD?**
 - a. Being unable to do something he once could do easily, such as get dressed
 - b. Being kept from doing something he thinks he is perfectly capable of doing
 - c. Not being able to see clearly enough to do things he once enjoyed, such as reading
 - d. Not being able to hear and understand directions
 - e. Working on a task he enjoys

3. **Fear and confusion often go hand-in-hand because a person who is confused about what is expected of him is likely to fear making a mistake and may therefore resist doing anything.**
 - a. True
 - b. False

4. **All of the following are examples of physical discomfort to watch out for in people with AD EXCEPT:**
 - a. Acute or chronic illnesses
 - b. Being hungry or cold
 - c. Depression or emotional pain
 - d. Medication issues (side-effects, wrong dosage, allergic reaction, adverse interaction of multiple medications)
 - e. All are valid

5. **Violence is a common symptom in people with Alzheimer's disease.**
 - a. True
 - b. False

- 6. People with AD may become anxious in a variety of specific situations. Which of these is NOT likely to be one?**
- a. We are invading their sense of personal space.
 - b. We have come upon them too quickly, from the side, or from behind, and they are startled by our sudden appearance.
 - c. We have tried to bring them into our reality instead of accepting their reality.
 - d. We are walking outdoors with them on a cloudy day.
 - e. We have given them a task to do which they are not certain they can do alone.
- 7. Many of the situations that produce anxiety in people with AD may also produce anxiety in us. Which of the following is LEAST likely to be a problem for most of us?**
- a. The back-breaking straw (A minor incident that sends us "over the edge")
 - b. Reality confrontation
 - c. Adaptive paranoia
 - d. Having our competency called into question
 - e. Having our personal space invaded
- 8. The role of the magician is to put herself into the mindset of the person with AD. That requires first and foremost knowing the person (his life story, routines, preferences, etc.) Understanding Alzheimer's disease is secondary to knowing the person.**
- a. True
 - b. False
- 9. The role of the detective is to figure out what caused the person's discomfort and how to prevent that discomfort in the future. Assume that a person does not want to take a shower. Which of the following questions is LEAST likely to be relevant toward putting him at ease?**
- a. Does he feel unsafe standing in the shower?
 - b. Is the temperature of the room or water uncomfortable?
 - c. Is he embarrassed accepting assistance from a female caregiver?
 - d. Is he accustomed to only taking baths and only on Saturday nights?
 - e. Does he like swimming?

Handout #3: Important Points and Resources

A summary of the discussion

Why is he doing that? There's a logical reason.

As people with Alzheimer's disease lose their verbal abilities, they tend to "speak" through their behavior.

- All behavior has meaning, but it is not always easy for caregivers to decipher that meaning.
- People with AD always make sense to themselves.
- When a person with AD seems anxious, agitated, or aggressive, or he is resisting care, first consider whether he might be tired, frustrated, fearful, confused, or physically uncomfortable.

Physical discomfort can have many causes

One of the primary problems with identifying physical causes of discomfort in people with Alzheimer's disease is that as their condition progresses, they have trouble "self-reporting."

- They are dependent on us to notice signs of pain, acute and chronic illnesses, dehydration, constipation, and depression.
- We must also be vigilant in noticing hearing and vision difficulties and behavior that could indicate an adverse reaction to the medications they are taking.

Violence is not a symptom of Alzheimer's disease

Years ago it was commonly thought that most people with Alzheimer's disease would eventually become violent. Now we know that barring a history of alcoholism or psychosis or a medication side-effect, people with AD who become verbally or physically combative, are essentially saying "No!" to whatever it is we are trying to get them to do.

- Violence in someone with AD always has an external cause, and often, we're it.
- Resistive behavior is a coping mechanism.
- People with AD who "resist care" are most often feeling frightened, confused, or uncomfortable. It is up to us to put them at ease before continuing.

Situational motivators

Another group of motivators are related to the reactions of people with AD to the situations they find themselves in. The list was inspired by Graham Stokes, an English clinical psychologist. When a person with AD seems anxious, agitated, aggressive, or resistive, he may be:

- alarmed
- uncertain about his competency
- living in a past reality
- using adaptive paranoia
- simply "at the end of his rope"

He may also misunderstand events or feel you are invading his personal space.

Personality can also play a role

- Some people's grumpy behavior is a reflection of their lifelong personality.
- Not all people are easy to like.
- Be kind anyway.

How do you know the real reason?

To understand the behavior of someone with Alzheimer's disease, Joanne Rader, in her book *Individualized Dementia Care*, notes that caregivers must take on four roles: magician, detective, carpenter, and jester.

- When a person with AD has difficulty expressing his unmet needs, become a magician: put yourself in his shoes, and learn all you can about him.
- When faced with a specific challenge, become a detective: ask where, when, who, what, and why.
- Then become a carpenter and build a solution with your team. If the solution doesn't work perfectly, modify the blueprint.
- Finally, become a jester. Look for ways to lighten the atmosphere.

Caregiver Tips: Brief advice

You may be a fabulous caregiver and still be surprised by a person's agitation or aggression. When this happens, try this:

- Stay calm in voice and body language.
- Back off. Respect the person's personal space. Offering regular opportunities to be outdoors often helps with this issue by creating a natural daily "cushion of air."
- Keep others away. Crowds – or feeling crowded – can increase agitation.
- Provide reassurance and a sense of safety.
- Ask the person directly what is troubling him. Try to identify the unmet need or the reason for his discomfort.
- Listen to his complaints, and affirm the feelings behind his words or behavior.
- When possible, solve the problem.
- Provide alternatives or redirect his attention. Remember the magician and the jester. What brings him pleasure? What will make him smile?

A resource list

In understanding what motivates behavior, the best sources are the people who have AD. Previous handouts have noted books by Cary Smith Henderson, Larry Rose, Ann and Robert Simpson, Lisa Snyder, and Kim Howes Zabbia, along with the video, *Inside Looking Out*.

One of the earliest – and still best – books of this genre is *My Journey into Alzheimer's Disease*, by Robert Davis (© 1988). Davis was a successful minister diagnosed with AD at age 53. His book has a strong Christian focus which may not appeal to all readers, but his chapter 7, "The Abnormal Changes So Far," is unsurpassed in clearly describing his experiences.

The two books cited in this session are:

- *Challenging Behavior in Dementia* by Graham Stokes (© 2000)
- *Individualized Dementia Care* by Joanne Rader (© 1995)

While Stokes has been an impressive leader in English dementia care, his book, intended for clinicians, is expensively priced and frequently unnecessarily complex. The information in this session was adapted (and simplified) from a chapter called "Taxonomies of possible explanations."

Rader also writes for professionals, but is much more accessible and reader-friendly. She is especially well-known for her work related to bathing people with Alzheimer's disease, and she was a pioneer in promoting restraint-free care.

