



Alzheimer's Awareness Family Night

HANDOUTS AND RESOURCES

SESSION #2:

Tuning in to Communication Challenges

Handout #1: Opening Exercise

Do you know what this says? It's a common problem when we are trying to communicate with someone with Alzheimer's disease.



Session #1:
The Importance of an Early Diagnosis and Understanding the Stages of Alzheimer's Disease

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. As Alzheimer's disease progresses, people tend to lose their verbal communication skills. All of the following are likely to be troublesome topics for conversation EXCEPT:**
 - a. Discussing what they ate for dinner last night
 - b. Naming their friends
 - c. Relating the number of years they worked at a career
 - d. Talking about the joys of grandchildren
 - e. Telling you the date of their next doctor's appointment

- 2. People with Alzheimer's disease often talk in generalities or talk around a subject rather than providing a specific answer.**
 - a. True
 - b. False

- 3. People with Alzheimer's disease who ask repetitive questions often:**
 - a. Have an unmet need (such as for a snack) that they are trying to express
 - b. Are purposefully trying to annoy us and should be ignored
 - c. Are trying to engage our attention by making conversation
 - d. All of the above
 - e. A and C only

- 4. Because of the damage to their brains, people with Alzheimer's disease are not usually embarrassed by their mistakes.**
 - a. True
 - b. False

- 5. Which of the following would NOT be a way to show common courtesy to someone with AD?**
 - a. Introducing yourself by name
 - b. Making eye contact and calling the person by name
 - c. Smiling and keeping your body language open and friendly
 - d. Continuing with other tasks, so that the person doesn't need to worry if his words come slowly
 - e. Including the person in your conversation when others are present

- 6. Vision and hearing impairment can contribute to challenges with communication. Which of the following is NOT recommended to try to overcome these challenges?**
- a. Stand or sit in front of a window so there is plenty of light.
 - b. Try to eliminate background noises.
 - c. Lower the pitch of your voice, especially if you are a woman.
 - d. Keep your voice calm and natural, even if you need to speak louder.
 - e. Speak slowly and distinctly.
- 7. Which of the following statements is true?**
- a. People with moderate stage Alzheimer's disease resist care because they are stubborn.
 - b. They resist because they are confused, frightened and/or uncomfortable.
- 8. Which of the following techniques is LEAST likely to bring you success when you are trying to assist someone with a daily task like dressing or grooming?**
- a. Issue an invitation
 - b. Tune into the person's feelings
 - c. Ask for his assistance
 - d. Leave and come back later with a new approach
 - e. Reason with him about the need for completing the task
- 9. We can boost the confidence of people with AD by showcasing their strengths. Which of the following is NOT likely to be one of those strengths?**
- a. Playing host by greeting people or passing refreshments
 - b. Reminiscing about her early life
 - c. Remembering what she ate for dinner last night
 - d. Enjoying jokes and laughter
 - e. Giving opinions and advice
- 10. Which of the following is NOT a good reason to be silent around someone who has Alzheimer's disease?**
- a. You are angry at your supervisor and not feeling talkative.
 - b. The person has a limited vocabulary and finds prolonged conversation tiring.
 - c. The person needs to use all her powers of concentration for completing a task, such as getting dressed or working on an art project.
 - d. Silent camaraderie is pleasant for both of you because you are at ease with one another.
 - e. There is pleasant music playing in the background and the person is enjoying it.

Handout #3: Important Points and Resources

A summary of the discussion

What is the person with dementia trying to say?

Communication skills diminish as Alzheimer's disease progresses:

- People with AD tend to have difficulty with nouns, names, and relationships.
- It's best to avoid asking questions related to short-term memory, numbers, and time.
- Because people with AD frequently live in a past reality or float in and out of the present, caregivers need to join them where they are and offer support and reassurance.

Watch out for hidden needs

- People who give "pat answers" may not be expressing their real needs. Caregivers must be clever and attentive to ensure those needs don't go unmet.
- People who ask repetitive questions may be requesting help in a roundabout way.
- Learning basic phrases in a person's native language, as well as watching for needs expressed in tone of voice, facial expressions, and gestures can be helpful to caregivers of those who speak English as a second language.

Humor still works

- Humor is a great communication tool for use with people living with AD.
- Never make fun of a person's feelings, but do look for ways to share the humor in everyday situations.
- People with AD enjoy smiles and laughter throughout the disease process, often making their own jokes and witty comments.

Effective communication begins with common courtesy

- Introduce yourself whenever you walk in the door. ("Hi, Mom. It's me, your daughter, Debbie.")
- Call your loved one by name or relationship to help her "tune in" to you.
- Make eye contact (sit beside him or crouch down to wheelchair height to position yourself at his eye level).
- Smile sincerely, and keep your body language open and friendly.
- Say "please" and "thank you" regularly.
- Give the person your full attention. (Multi-tasking while someone is speaking makes them feel unimportant, even invisible.)
- When others are present, be sure your loved one is not excluded from the conversation.
- Never speak about your loved one with AD in the third-person when she is present. ("Mother doesn't like milk in her coffee.")
- Give your loved one the opportunity to make meaningful contributions to the conversation by including him in discussions and asking for his opinion and advice.

Making your message clear:

- *Expressive aphasia* is the loss of the ability to speak coherently. *Receptive aphasia* is the loss of the ability to understand what is being said. Processing for both speech and understanding slows down with AD.
- People with AD tend to understand much more than they can express. Don't say anything you don't want them to understand.

10 basic strategies guidelines for effective communication:

- 1) Use short sentences that state what you want in positive terms. If someone says, "Don't think of pink elephants," the first thing that comes to mind is pink elephants, so always say what you want ("Please stay inside") instead of what you don't want ("Please don't go outside.").
- 2) Be patient, and don't rush the person. One woman with AD creatively made up the word "flustrated" – a combination of flustered and frustrated – to describe how she felt when she was rushed.
- 3) Give directions one step at a time. Information overload happens quickly in people with AD, and simple directions are much easier for a person to follow successfully.
- 4) Give the person time to "tune in" to what you're saying. Many people have had the experience of calling to someone from another room and getting no response. It takes a person with AD longer to register the fact that he is being addressed, which is why standing in front of him, calling him by name, and making eye contact with him are key elements of effective communication.
- 5) Use the same words when you have to repeat a phrase. If you rephrase a question, a person with AD still puzzling over the last question will likely perceive your revised words as a new question and find it "flustrating."
- 6) Use concrete words. "Put that over there," may be confusing to a person with AD. Instead, try, "Please put the newspaper on the coffee table."
- 7) As AD progresses, avoid open-ended questions. Early in the disease process, it is usually fine to use open-ended questions, such as, "Tell me about your family" or "What are some of your favorite foods?" Later in the disease process, however, it is better to substitute questions that require only "yes," "no," or short phrase answers, such as, "Do you have any grandchildren?" or "Do you like Italian food?"
- 8) Limit choices. "Would you prefer the grilled cheese sandwich or the tuna sandwich?" is easier for people with dementia to answer than, "What would you like for lunch?"
- 9) Provide multi-sensory cues to increase the chances that a person will understand the meaning behind your words. For example, bringing a towel and soap into the person's room when it is time for a bath provides a cue about what's to come, even if the words "It's time for your bath" don't completely register.
- 10) As dementia progresses, avoid expressions you don't want taken literally ("It's time to hop into bed."), and recognize that metaphors may be confusing or distracting. ("It's so hot you could fry an egg on the sidewalk.").

Vision and hearing may also be a problem

Many communication challenges are caused by vision and hearing impairments.

- You are more likely to be understood if you face the person at eye level, speak slowly, calmly, and distinctly, and lower the pitch of your voice.

Beyond the basics

- People with AD who “resist care” are most often feeling frightened, confused, or uncomfortable. It is up to us to put them at ease.
- Honor the person’s right to say “no.” Coming back later for a fresh start is often a good strategy.
- Issuing invitations or asking the person for assistance can often turn situations around. Everyone needs to feel useful and valued.
- We can also ease tension by taking the blame for miscommunications.

Boost the person’s confidence

- Showcase their strengths; tap into remaining memories and social skills.
- Avoid putting them on the spot.
- Ask for their advice and opinions.
- Let them set the scope and pace of the conversation.
- Use and encourage humor.

Silence can be golden:

- For some people with AD, talking while trying to perform a task is distracting
- For others, conversation can be exhausting.
- Silent camaraderie can be a friendly and welcome alternative to talking.

A resource list

During this session a number of resources were quoted that seek to help us understand Alzheimer's disease through the eyes of those living with it:

- *Alzheimer's Disease: Inside, Looking Out* is a 19-minute video featuring people with AD from the Cleveland Area Chapter of the Alzheimer's Association. Available through Terra Nova Films at 800-779-8491 or <http://www.terranova.org>.
- *Perspectives* is published quarterly by the Shiley-Marcos Alzheimer's Research Center at the University of California, San Diego. Sign up for free online copies by sending an email to adrc@ucsd.edu and access past issues at <http://adrc.ucsd.edu/newsletter/news1.htm>.
- *Painted Diaries: A Mother and Daughter's Experience Through Alzheimer's* by Kim Howes Zabbia, © 1996.
- *Partial View, An Alzheimer's Journal* by Cary Smith Henderson and Nancy Andrews, © 1998.
- *Show Me the Way to Go Home* by Larry Rose, © 1996.
- *Speaking Our Minds, Personal Reflections from Individuals with Alzheimer's* by Lisa Snyder, © 1999.
- *Through the Wilderness of Alzheimer's: A Guide in Two Voices* by Robert and Ann Simpson, © 1999.

The books listed above are available used online, if not in stores.

A few excellent resources for understanding in greater detail how to communicate effectively with people living with AD are:

- *Care That Works: A Relationship Approach to Persons with Dementia* by Jitka Zgola, © 1999.
- *Navigating the Alzheimer's Journey* by Carol Bowlby Sifton, © 2004.
- *Rethinking Alzheimer's Care* by Sam Fazio, Dorothy Seman and Jane Stansell, © 1999.
- *The Best Friends Approach to Alzheimer's Care* by Virginia Bell and David Troxel, © 1997.

