Families Need Ideas

KEY POINTS

| Families frequently need guidance about what to say and do when they visit a loved one with AD in a residential care setting. |

| They particularly need help understanding how to converse without asking questions that highlight the short-term memory loss of people with AD. |

| They also need to be encouraged to communicate non-verbally. |

One daughter recalls that whenever she accompanied her father on visits to her mother in the nursing home, he would sit on a couch in the lobby with his wife for 20 (mostly silent) minutes, and then get up and leave, proclaiming, “Well, THAT was an exercise in futility!” Because, in the late stage of Alzheimer’s disease, her mother’s verbal skills were severely limited, her father didn’t realize that his simple presence and reassuring voice provided the same comfort to her as it had for the past 50 years of their marriage.

Most of us are likely to expect that the spouse and children of a woman with AD would find it easy to visit with her in a residential care setting. After all, they know her best. But we might be mistaken. When the woman was living at home, both her husband and any visiting adult children probably devoted most of their time to direct caregiving tasks or household chores such as cooking, cleaning, paying bills, or mowing the lawn.

In other words, they became used to being useful. In a residential care setting, however, these tasks are accomplished by staff, leaving families at a loss for how to spend time with the person.

Perhaps as a result, family members often inadvertently ask questions that lead to unnecessary crises. While visiting her mother with AD, Susan, merely intending to make small talk, asks, “What did you have for lunch?” Since her mother does not remember what she had for lunch, she assumes she missed lunch and says so. Taking her mother at her word, Susan worries and thinks, “My mother didn’t have lunch? Did they forget that she needs assistance finding the dining room? Is she being left to starve?” In a panic, Susan storms to the administrator’s office. The administrator must then find a delicate way to tell Susan to avoid questions that call attention to her mother’s short-term memory loss.
CAREGIVER TIPS

CREATE A GOOD-BYE RITUAL

Family members also need help to avoid awkwardness in leave-taking. Here are three quick tips for family caregivers who visit:

• Develop a leave-taking routine that suits you. Perhaps it is holding the person's hand and singing, "Goodnight My Someone," kissing her cheek and saying, "Sweet dreams, Sweetie. I love you," and then walking out the door.

• Give the person a reason to say goodbye to you. Time your visit so your departure coincides with the beginning of an activity the person especially enjoys.

• Leave a reminder of yourself to provide tangible comfort until you return - a photograph, a greeting card with a message for her, a scarf or sweater that she associates with you.

Finally, encourage family members to cut themselves some slack and to postpone visits when they are exhausted or stressed.

Families Need Ideas

Some family members also "grill" their loved ones, believing it is their responsibility to orient their loved ones with dementia to reality. These family members ask questions such as, "Who am I?" or "What day is it?"

The person with dementia may or may not know the answer, but is frequently frustrated, confused, and shamed by the question. (When one woman's daughter asked, "What's my name?" the woman said, "I don't know, dear, but if you can't remember you can ask that nice young lady at the front desk.")

You can help families have more successful visits by educating them about the pitfalls of reality orientation and coaching them to make changes in their approaches:

• Suggest ways families can naturally introduce themselves as they greet a loved one. "Hi, George. It's me, your ever-lovin' wife, Doris, coming to have lunch with you."

• Let them know that asking, "What did you do today?" puts the person with AD on the spot. Asking, "How was your day?" is a much easier question to answer.

KEEP IN MIND: BE PRO-ACTIVE IN HELPING FAMILIES

As staff, you can help families have good visits by letting them know what activities their loved one enjoys:

• Send Polaroid or digital pictures to family members showing their loved one participating in activities. Attach a short caption: "Your mother was quite the card playing Crazy 8s!" (If you adapted the rules of the game so that she could be successful, teach the family to do the same.)

• Greet arriving family members with good news to set a positive tone for their visit. The message can be simple: "He's had a big grin on his face all day today."

• Remind them that smiles, hugs, hand holding, and an arm around a shoulder are almost always more deeply appreciated than words by the person with AD.

Key Point:
Be pro-active in giving families ideas for having good visits by sending pictures of their loved one in an engaging activity, setting a positive tone when they visit, and highlighting the activity calendar with events he enjoys..
Ideas for Families

As staff, the most important thing you can do to help families have good visits is to make them feel welcome. No matter how tough your day has been or how challenging certain family members have been in the past, put on a happy face when you see them. Offer a cup of coffee or a glass of juice. Find something positive you can say about their loved one’s recent activities. When families are comfortable in your setting, it is easier for them to believe their loved ones are, too.

As we noted in a previous newsletter, some family members can be helped to have a good visit by:

- Continuing their caregiver role in some way, perhaps by helping to feed or bathe their loved one
- Participating with their loved one in a group activity such as a craft class
- Attending a social event or outing sponsored by the residential community

But there are many other possibilities. Encourage family members to:

- **Check out local areas of interest** with their loved one by providing families with a list of and directions to nearby restaurants, museums, botanical gardens, parks, historical sites, etc. (If possible, provide brochures, take-out menus, and information on bathroom accessibility.) Or they might like to just take a joy ride!
- **Bring in a special snack for their loved one** - an elaborate ethnic dish, a favorite family recipe, or a milkshake from the local Dairy Queen may be equally welcome.
- **Bring in a project to work on with their loved one**, such as junk jewelry to sort or laundry to fold. Make party favors for a grandchild's birthday, or clothespin reindeer for the church holiday bazaar.
- **Bring along reminiscence-enhancers** such as an old photo album, trip souvenirs, or a grandchild's outgrown baby clothes. Find a coffee table picture book representing the person's favorite hobby or pastime.
- **Use the activity supplies you have on site.** Share what you know about the games and activities their loved one enjoys - croquet, badminton, or checkers, for example - and make sure family members know where to find these items when they visit.

- **Get some exercise together.** A simple walk outdoors can do wonders for both body and spirit.
- **Enjoy music together.** Try out some rhythm instruments - shake, strum. Dance. Sing. Or just listen to the person's favorite melodies together.
- **Bring along grandchildren** and watch them play.
- **Read aloud.** Making conversation with a person with drastically limited verbal skills is difficult, but family members need to know their voices alone provide comfort. Reading poetry, funny anecdotes, or inspirational texts aloud takes pressure off the person with AD to make conversation, but allows them to hear a loved one's voice. (The Reader's Digest column, "Life in These United States" provides brief, interesting tidbits that work well for people with AD.)
- **Be present.** Many couples didn’t talk much in the evenings; they simply spent time together. Perhaps they watched a favorite television program; perhaps the wife did her knitting and the husband polished shoes or read the newspaper. Old routines can still work. A good visit doesn’t always require intense interaction.

**KEY POINTS**

- One of the most important ways to help families have good visits is to make them feel welcome in your residential community.
- Some family members are most comfortable participating with their loved one in group activities.
- Others need ideas for one-on-one interaction which can include many ideas from outings, exercise, eating, making music, and reading to simply being present.

**RESOURCES**

* A Different Visit: Activities for Caregivers and Their Loved Ones with Memory Impairments, was written by Cameron Camp, PhD, director of the Myers Research Institute (MRI) near Cleveland, along with several of his colleagues, (Adena Jotlin is listed as lead author) in 2005. The book is based on activities the MRI staff successfully implemented with people with Alzheimer's disease using Montessori principles, such as working to the level of an individual's ability. It is written for a person who is in about mid-stage AD, but each activity comes with ideas for making it more or less challenging. Order the book, or learn more at http://www.myersresearch.org under "products."
The “Trainer’s Corner” helps you relate the topic to caregivers’ personal experiences in order to make it relevant and memorable. With each issue, we will provide discussion questions and an engaging exercise. A quiz is available on Page 5 to test participants’ knowledge. (The answers appear on the bottom of this page.)

Bringing the lesson home

Mel Brooks’ western comedy, Blazing Saddles, has a scene where the bad guys are chasing the good guys across the desert and catching up fast. To foil them, the good guys quickly set up a toll booth. The bad guys discover they don’t have enough nickels for the toll and have to send one of their gang back to town for more. In the meantime, the good guys get away.

The scene is silly, because, of course, the bad guys could have simply ridden around the toll booth. The desert provided plenty of open land. But in real life, we all set up toll booths - obstacles - that we don’t question. We have been taught to play by the rules and pay the toll. We seldom stop to think that the toll may not be worth paying, or that we have other options.

Let’s talk

The above story teaches a lesson that is important in many life situations:
Imagine other possibilities.
However, for the purposes of this exercise, ask participants to focus on activities and how they can be adapted for people with Alzheimer’s disease. Games have rules, and many involve keeping score. Yet people with AD almost always have difficulty following rules and adding up numbers.

Ask participants to look at the list of activities below (or to choose an activity that is not listed that they enjoy) and figure out ways to eliminate the rules or bend the rules so that someone with Alzheimer’s disease might enjoy playing it:

- Badminton
- Dominoes
- Bingo
- Fill in the blank (word games)
- Bowling
- Go Fish
- Charades
- Horseshoes
- Chutes and Ladders
- Lotto
- Connect Four
- Scrabble
- Crazy Eights
- Shuffleboard
- Croquet
- Yahtzee

If they have already had success in adapting various games, encourage them to share those experiences. Finally, ask them how they might teach these adaptations to family members who may not realize that there are other options besides playing by the traditional rules.

Answer Key for Quiz on Page 5

1) c
2) a
3) b
4) d
5) e
Please answer the following questions based on the information on the previous pages.

1) Families often have difficulty knowing how to visit with their loved one in a residential care setting for all of the following reasons EXCEPT:
   a. In the past they had household chores to do when they visited
   b. They have a tendency to ask questions that the loved one can’t answer due to short-term memory loss
   c. They don’t really want to spend time with their loved one
   d. Some family members think it is their role to test their loved one by asking questions related to names and dates
   e. They haven’t had much practice in adapting the rules of games to help their loved one be successful

2) One of the best things you can do to help family members have good visits is to make them feel welcome in your residential care community.
   a. True
   b. False

3) Some families are more comfortable visiting their loved one if they can participate in a group activity. Which of the following is an appropriate example of this?
   a. Accompanying their loved one on a group outing
   b. Playing the piano for a sing-along
   c. Assisting the leader with a craft project
   d. All of the above
   e. A and B only

4) All of the following are likely to be appropriate one-on-one activities a family member can do with their loved one when they visit EXCEPT:
   a. Going for a drive
   b. Playing Bridge
   c. Taking a walk
   d. Sitting quietly on the porch, rocking and holding hands
   e. Reading aloud the poems of Emily Dickinson

5) Which of the following is NOT a good idea for how family members can end a visit smoothly?
   a. Leave behind a reminder of themselves, such as a hand-written note or a sweater
   b. Suggest they must leave now to take care of an emergency at home
   c. Time their leave-taking to coincide with the beginning of an activity their loved one enjoys.
   d. Create a good-bye ritual such as always singing, "So Long, Farewell" from the Sound of Music.
   e. All are valid.