



Alzheimer's Awareness Family Night

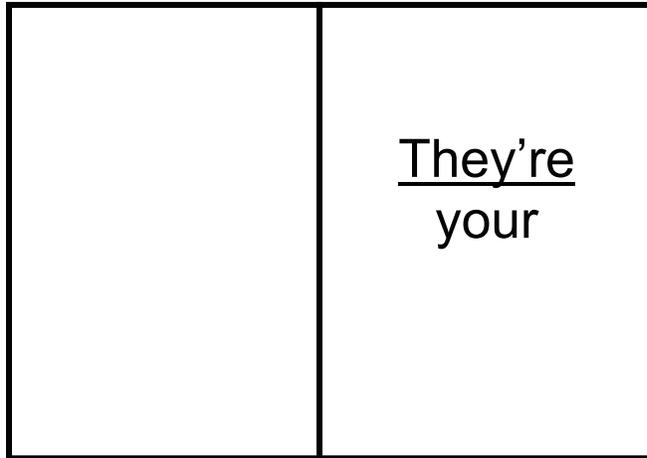
HANDOUTS AND RESOURCES

SESSION #7:

Making the Residential Care Decision Work

Handout #1: Opening Exercise

What does this say?



Handout #2: No-Pressure Quiz

- 1. Family members who place a loved one in a residential care setting are almost always grieving, even if they don't realize it. Which of the following is NOT something they are likely to be grieving about?**
 - a. The loss of their loved one's independence
 - b. The loss of the relationship they once had with one another
 - c. The changes in the person's lifestyle that automatically come with residential living
 - d. Their inability to continue caring for the person at home
 - e. The curtailment of sleepless nights

- 2. Now that Alzheimer's disease has become well-known, family caregivers are usually good at seeking out help when they need it.**
 - a. True
 - b. False

- 3. "Trigger issues" are problems that lead to catastrophic outbursts by people with Alzheimer's disease.**
 - a. True
 - b. False

- 4. Family members tend to have many different viewpoints because they have diverse experiences with the person with AD. Therefore, in family disagreements, the majority should rule.**
 - a. True
 - b. False

- 5. While it is likely that there will still be problems to solve when a person moves to a residential care community, there are also likely to be many benefits. Which of these is not usually one of them?**
 - a. The resident is likely to benefit from the activities and socialization in residential care
 - b. The resident is likely to benefit from a calmer and more structured environment
 - c. The resident is likely to experience a reversal of his memory loss
 - d. The family caregiver is likely to be able to enjoy more relaxing visits with his/her loved one
 - e. The family caregiver is likely to be able to resume some of the pleasurable pastimes that were neglected when he/she was a full-time caregiver

Handout #3: Important Points and Resources

A summary of the discussion

The diagnosis

- When people are given a diagnosis of Alzheimer's disease, it is usually initially devastating.
- It causes multiple changes both in the life of the person with the diagnosis and his or her family and friends, especially those playing a caregiving role.
- It is not uncommon for families to pass through various stages of grief such as denial, anger, sadness and bargaining as they adjust to these changes.
- At the very least, there tends to be a yearning for what was and for the future they envisioned.
- In time, however, the shock wears off and people learn to live with the Alzheimer's disease and each other.

Facing a Move to Residential Care

- Many family caregivers wait too long to seek help for a variety of challenges they face, meaning their lives might have been easier if they had sought help earlier.
- Families tend to be particularly reluctant to make the decision to move a loved one into a residential care community because they often see it as an admission of failure.
- Even when family caregivers have seriously damaged their own health by caring for a person with AD – and recent studies show that the responsibilities of caregiving can shorten a person's life by several years – they still almost invariably feel they ought to have been able to provide care on their own. The fact that in a residential care community their loved one has multiple staff to perform the tasks they were attempting alone doesn't seem to matter.
- Therefore, spouses and family members frequently face move-in day with a bittersweet mixture of guilt and relief.
- There will always be a time of adjustment when someone moves to a residential care community, but many family members are surprised to see their loved ones thrive in a community that is simple, structured, and more slowly paced.

Adjusting to New Challenges

- Even when a person makes a smooth adjustment, problems will still arise, and when they do, family members frequently question their judgment. ("Have I done the right thing?")

- “Trigger issues” are seemingly modest problems that mask deeper concerns and trigger disproportionate reactions from family members. When something goes wrong, the problem becomes symbolic of the loss of control over your loved one’s care and the need to trust strangers to keep her from harm.

When these minor mishaps happen – and they will – try to examine your feelings. You should be able to get the problem satisfactorily resolved, but if you are unusually upset, perhaps it’s because:

- You are afraid that laundry issues are indicative of larger care issues. Or
- You have had a bad day or week, and are feeling like you’re at the end of your rope. Do you need someone to solve the problem *and* offer some words of comfort to you? Or
- You have been getting grief from other relatives and friends about your decision.

If you’re concerned that minor problems are indicative of a larger competency issue, share your concerns with the nursing director or administrator. Be specific about what you’ve observed and what you think needs to be done. Confidence in a community isn’t built because there are no problems, but because problems raised are taken care of to your satisfaction.

If you are at the end of your rope, and you need a hug or a listening ear on a bad day, you would be amazed how happily most staff will comply. The goal for staff and family members is to become a team.

Families Are a Varied Lot

- Today’s families are often complex and may include multiple marriages, stepchildren, ex-sons or ex-daughters-in-law, adopted grandchildren, or gay or lesbian partners.
- Each of them may harbor unique agendas, jealousies, and fears. They seldom speak as one voice.
- If you are the primary caregiver, don’t let these lesser involved relatives sap your energy or make you question your judgment.

The Good Times

- Most people’s lives are filled with busyness, running here and there; however, people with Alzheimer’s disease tend to thrive in an environment that is calm, structured, and more slowly paced than most of us can provide. Residential care communities tend to be very good at providing this type of environment.
- Families frequently focus on the person their loved one *used* to be. Staff members have no sense of loss for what he once was; they simply accept the person who has moved in as he is.
- They also can be helpful in reframing behavior. The example used in class was describing a man with boundless energy as “spirited.”

- Residential care frequently offers the socialization and gentle stimulation that were missing in an isolated home life.
- Family members may benefit from placing a loved one in a residential care setting because they can rebuild a relationship based on friendship instead of being consumed with caregiving issues.

Family Members Can Help Staff

- Knowing the individual who has the disease can be more important for quality care than having a thorough knowledge of Alzheimer's disease.
- As family caregivers, you can be enormously helpful to staff by providing information on your loved one's habits, routines, preferences, personality, interests, and life story. You know details that can be helpful in daily care that no one else knows. Most of this doesn't come out in a survey, but over time in hallway conversations.
- We hope that staff will turn to you for advice on how you managed anything they are having trouble with, such as bathing, when you were the primary caregiver. If they don't, you can volunteer your tricks of the trade, and they will usually be grateful. Staff who don't know you well may be afraid to admit they are having a problem.
- Be sure to share the positive qualities of your loved one with staff. If you know your mother as someone who has always been willing to help, fun-loving, and gentle, let staff know so that they can draw out those qualities in her.
- If you want to continue a caregiving role once your loved one has moved into a residential care community, make your wishes known. A man who comes in daily to lovingly feed lunch to his wife provides nourishment for her body *and* her spirit, and is helping his own spirit, too. Do what's best for you.

A resource list

In this session, three resources written by Ann Davidson were referenced. Most of the quotes came from an article in the quarterly journal, *Alzheimer's Care Today*, (October – December 2007, pages 294-300) titled, "Alzheimer's Disease: One Family's Story." She is also the author of two books: *Alzheimer's: A Love Story: One year in My Husband's Journey* (© 1997) and *A Curious Kind of Widow: Loving a man with Advanced Alzheimer's* (© 2006). Mrs. Davidson's husband, Julian, was a research scientist at Stanford University when he was diagnosed with Alzheimer's disease at age 59. He died 12 years later, in 2001. Mrs. Davidson is also a cancer survivor.

The ideas for much of the rest of this session were taken from the writings of Kathy Laurenhue, particularly two of her books:

- *Getting to Know the Life Stories of Older Adults: Activities for Building Relationships* (© 2007, Health Professions Press)
- *Alzheimer's Basic Caregiving – an ABC Guide* (© 2006, Wiser Now, Inc.)

