



► Families advocating for their loved ones are considered

"customers."

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► "Caregiver Tips" offers practical suggestions for caring for people

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► Many caregivers are more than willing to get to know their care

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► Families faced with their loved one's Alzheimer's disease rarely

speak as one voice.

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# ALZHEIMER'S *In-Service*

## M O N T H L Y

BEST PRACTICES IN RESIDENT-CENTERED CARE

VOLUME 15 | 2009

## Families Are Confronting Loss

### KEY POINTS

- Family members who place a loved one in residential care often experience grief.
- They grieve for the person's loss of independence and for the loss of the relationship they once had with that person.
- Grief often transitions to guilt over feeling unable to continue home care. That guilt may be expressed through doubts about the quality of care residential settings can provide.

In residential care communities, day centers, and other organizations serving people with Alzheimer's disease, families advocating for their loved ones are considered "customers." Building relationships with them is as important as building relationships with the person who has AD. To do so, it is vital to understand that those family members are grieving, even if they don't realize it themselves.

This grief has at least two aspects. First, they are probably grieving on behalf of the person who has lost his independence. If the person with AD is now living in a residential care setting, families are likely to feel sorrow that his familiar surroundings, friends, and routines are largely gone. Families are also aware that the person has lost his privacy with regard to intimate care needs, as well as his public status and image.

Second, families grieve their own losses. Spousal caregivers mourn the loss of the constant companionship of a husband or wife. Adult children lament over no longer having parental guidance and support. If the family member has been the primary caregiver, a move to a residential care setting signifies a loss of that role, and that family member may feel a significant void. Most of all, though - whether spouse, adult child, or friend - caregivers yearn



for the person their loved one used to be and the life they once had.

Thoughts of these losses often turn into guilt over being unable (or unwilling) to continue to provide care at home when needs become more complex. 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. Making a decision to move a loved one to a residential care setting or to enroll that person in a day center is frequently seen as an admission of personal failure.

# CAREGIVER TIPS

## BE A RESOURCE CENTER

If Mrs. Brown is having trouble with her husband's laundry, she wants to know where she can turn for help. Invariably, family members appreciate being given a list of phone numbers and email addresses for key staff. You can take the idea of providing resources even further. For example:

- Be a repository for brochures and other publications from "disease associations" such as Alzheimer's, heart, and diabetes. At the very least, provide the phone numbers of local organizations that serve those conditions. (Providing these is also a good marketing tool.)
- Offer a lending library of current best resources on issues related to elder care. Make sure at least some of those provide upbeat messages on aging. (See Resources.)



## Families Are Confronting Loss

FROM PAGE ONE

Thus, no matter how close to perfect a residential care setting may be, family caregivers are still likely to question their decision every time their loved one's hearing aid is misplaced or her new outfit comes back faded from the laundry. Listen and respond to their concerns, try not to take their doubts personally.

Instead, recognize that these are "trigger issues" - seemingly modest problems that mask deeper concerns and trigger disproportionate reactions from family members. If Mrs. Smith's new outfit is faded, the issue is probably not really a ruined outfit. Rather, since laundry seems like a fairly simple task, a daughter might wonder, "If staff can't get the simple stuff right, how can I have confidence that they are getting the tough stuff right? How can I be certain my mother is getting quality care?" In this situation, laundry is symbolic of the daughter's loss of control over her mother's care and her need to trust strangers to keep her mother from harm.

Because little mistakes can create major misgivings, it's important to know family members' trigger issues, to address them up front, and to solve them whenever possible. A little proactive problem-solving can go a long way. Additionally, be sure to provide a listening ear for deeper concerns. Sometimes families aren't looking for answers or change. They don't need us to tell them things are going to get better when their loved one is clearly deteriorating. They just need us to listen as they express their grief and emotional turmoil.



## KEEP IN MIND: FAMILY MEMBERS CAN BE EXCELLENT TRAINERS

David Troxel points out that family caregivers have been coping with the quirks of their loved ones for years. They should be the first place you turn for ideas when you have a challenge with a resident. Mr. Smith doesn't like bathing? How did his wife manage this task when he lived at home?

You can also take this a step further by actually involving the family member in staff training. Gather staff together, and let the family member give suggestions to housekeepers, dining servers, direct care workers, and activity staff, for example.

Some family caregivers want to maintain an active caregiving role. A man who comes in daily to lovingly feed lunch to his wife provides nourishment for her body and her spirit.

### Key Points:

When challenges occur, families can be helpful sources of assistance.

Use family members' knowledge of what works for their loved one to provide advice and training to staff.

Find ways for family members who wish to continue to have an active caregiving role to do so.

# Families Rarely Speak As One Voice

Families faced with their loved one's Alzheimer's disease rarely speak as one voice.

- Spouses often cover up for their partner.
- Adult children who live far away may over-estimate or under-estimate their loved one's disability.
- A beloved son may not be ready to face the deterioration of his parent and, to buy time, denies the problem.
- An estranged son may be unwilling to help his overburdened sister with the care his father needs.
- An uninvolved daughter may lay guilt on her overburdened mother about the care of her father. ("You can't move him to a facility. You promised him you would take care of him at home!")

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. Many of these people require individualized nurturing due to their own agendas, jealousies, and fears. However, there is usually one primary caregiver (most often the spouse or adult daughter). Focus on this person, and work with the others as well as you can.

David Troxel, a consultant who co-authored the "Best Friends" series of books on Alzheimer's care (See Resources) makes two points:

- 1 Don't judge or second-guess families. "We need to take families as they are, give them education, give them good information and hope they make good decisions." When they don't respond as we might wish them to, they probably have their own reasons. Many adult children have conflicted relationships with their parents, and not all marriages are ideal.
- 2 Avoid giving advice. "Families, when they ask advice, typically either want someone to agree with them because they've already made up their minds, or they want someone to blame when it goes wrong."

And when one family member proves particularly difficult to deal with, take comfort from the fact that the person is likely difficult for

his or her family members to deal with, too!

The best way to meet the varying needs of family members is to ask them directly what they want, and do your best to provide it. Chances are, those wants will evolve over time. Family members' move-in day priorities will almost certainly differ from their priorities a year later. On move-in day they may have multiple concerns, feel overwhelmed, and overwhelm you. Encourage them to focus on one thing at a time, reminding them that Rome wasn't built in a day, and that perfecting their loved one's care will happen with conscientious effort and open dialogue over time.

The ways families stay involved with a loved one's care will also change. Keep the lines of communication open, and offer a wide range of opportunities for family involvement - social events, educational seminars, volunteer opportunities, and support groups. A spouse intimidated by the complications of taking her husband to a concert or restaurant may be delighted to accompany him on a group event if the responsibility for his care (including getting him to the restroom) is shared. In addition, she is likely to appreciate the social interaction with other family members, because, sadly, old friends frequently drift away when someone has AD.



## KEY POINTS

- | Family structures are complex and involve diverse relationships between various members and the person needing care.
- | Treat the needs of family members individually, but concentrate on the primary family caregiver.
- | Don't judge family members' actions or decisions, and avoid giving advice.
- | Family members you find challenging are likely challenging for their families, too.

## RESOURCES

The "Best Friends" series of books on Alzheimer's care by Virginia Bell and David Troxel are excellent and available from Health Professions Press ([www.healthpropress.com](http://www.healthpropress.com) or 888-337-8808). If you choose to provide a lending library to family members, we suggest that you include some upbeat books on aging. Here are a few available through Amazon.com or your local bookstore:

*The Creative Age and The Mature Mind*, both by Gene Cohen, M.D., Ph.D.

*Up Words for Down Days*, by Allen Klein

*Heart Humor and Healing*, edited by Patty Wooten, R.N.

*Age Doesn't Matter Unless You're a Cheese*, edited by Kathryn and Ross Petras

# TRAINER'S CORNER

## IN-SERVICE GUIDE

*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

Draw this simple illustration on a white board:

their	I'm your
-------	----------



Ask participants what it says. Can they figure it out? It's a word puzzle for the phrase "I'm on your side." It's one of the most important messages staff can convey to families.

To help foster understanding, ask staff:

- If you moved into a residential care setting tomorrow, what changes would be hardest to adjust to? What losses would you feel?
- If you were a family caregiver, what self-doubts might you have about moving your loved one into residential care?

Then ask these questions about their own families:

- When a big decision must be made in your own family, do you all agree?
- Which family member is known for getting things done?
- Which family member is most likely to disagree with the decision?
- How do you deal with the person who disagrees?

### Let's talk

Most people don't go to work each day thinking, "I'm going to see what a mess of my job I can make today," so when we are criticized by family members it is hard not to take the criticism personally and hard not to see the family member as an adversary. The goal of this lesson is to help participants see through the eyes of family caregivers. Most of us probably think the idea of having someone provide three meals a day for us is appealing, but would we really like to live in a place where we couldn't just jump in the car and pick up a burger and a shake whenever we wanted? Probably not. Give participants a chance to name all the reasons they wouldn't want to live in their residential care community - all they are giving up in freedom, lifestyle, and privacy - and help them to see that those are many of the same reasons family caregivers have self-doubts and guilt about placing a loved one there. Family members' feelings are often related less to what staff does than to the reality they cannot change.

Thinking about their own families helps staff to understand that decision-making - even among people who love each other - is a messy business.

### Answer Key for Quiz on Page 5

1) e   2) b   3) b   4) d   5) c

# QUIZ: What Motivates Families?

PLEASE COPY AND DISTRIBUTE TO EACH PARTICIPANT

\_\_\_\_\_

First Name

\_\_\_\_\_

Last Name

\_\_\_\_\_

Quiz Date

\_\_\_\_\_

Supervisor's Signature

\_\_\_\_\_

Date

*Please answer the following questions based on the information on the previous pages.*

- 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) Trigger issues are problems that lead to catastrophic outbursts by residents.**
  - a. True
  - b. False
  
- 3) Family members tend to have many different viewpoints because they have diverse experiences with the person with AD. Therefore, in family disagreements, it's best to side with the majority.**
  - a. True
  - b. False
  
- 4) It is not a good idea to get involved with giving families advice because:**
  - a. The person asking may not really want advice; she likely wants someone to agree with her viewpoint
  - b. The person asking wants someone to blame if things don't turn out well
  - c. The person may be looking for ammunition to take back to the rest of the family
  - d. All of the above
  - e. A and C only
  
- 5) Family members may want to continue an active caregiving role in some way. Which of the following probably would NOT be appropriate?**
  - a. A resident's daughter helping to feed her mother
  - b. A resident's son giving staff advice about bathing his father
  - c. A resident's wife assisting with the toileting of various residents
  - d. A resident's grandchild assisting with a sing-a-long
  - e. A resident's husband accompanying the group on an outing to a nature trail

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