

Transitions: From Home to Facility Care by Bobbi Turner, Community Outreach/Education Coordinator, Alzheimer's Association Great Plains Chapter

Admitting that you are no longer able to take care of a loved one at home is an intensely difficult and emotional event. The transition from care partnering in the early stages, to care giving and the need for a professional level of care is often a very gradual event. Often times the caregivers own health is being compromised which precipitates the decision for placement in a facility environment. This is a time when family support is crucial for the primary caregiver. The family should come together early in the process to explore all the options available and to support each other and the primary caregiver in this very difficult decision.

When is the right time for facility care? This is a difficult question to answer and is different for each individual situation. There are several factors to consider and whenever possible it is important to include the person with Alzheimer's in the final decision. There are several important issues to think about when considering placement for a loved one.

- **Safety**-Has the person with AD had accidents with smoking, the stove or other appliances? Are they able to get around the house easily without falls or extensive help walking? Is the home environment becoming more difficult, ie: dark hallways, stairs accessible doors.
- **Personal Hygiene**-Is it difficult for you loved one to get to the bathroom when needed? Are they unwilling to bathe? Are they unwilling to change clothing when needed? Have care needs for your loved one become too difficult or too demanding for you? Are they unable or unwilling to help with personal care tasks?
- **Behavioral Concerns**-Has your loved one ever wandered away from home or been lost? Is your loved one combative, suspicious, angry, or refusing care? Have they physically harmed themselves or you in the past?
- **Nutrition**-Does the person with AD have trouble preparing meals or eating independently? Do you have difficulty encouraging your loved one to eat appropriate, nutritious foods? Is your loved one having health problems associated with poor nutrition? Ie: weight loss, illness, dehydration, vitamin deficiency. Has eating and swallowing become difficult for the person with AD?
- **Time and Energy**-Does your loved one need help with most ADL's, eating, bathing, dressing or personal hygiene? Do housekeeping duties need to be done so frequently that care becomes an excessive demand? Have you frequently lost sleep at night due to caregiving?
- **Financial Concerns**-Have the financial strains of caregiving been difficult on your personal budget? Ie: medical equipment, incontinence, food. Do you miss work frequently due to caregiver responsibilities?
- **Caregiver Issues**-At the end of the day, have you felt like you couldn't make it through another? Is this a recurrent thought? Is your health at risk or beginning to suffer because of your caregiving responsibilities? Have you lost privacy or the ability to organize and run your household? Is there frequent conflict between household members related to caregiving issues? When you get a break from caregiving, do you still feel overwhelmed and exhausted?
- **In Home Care**-Have you tried and been unsuccessful with in-home services such as housekeeping, delivered meals, personal & companion care? Have you had difficulty getting your loved one to attend adult day programs? Has overnight respite care been used? Have you had difficulty enlisting the assistance of family and friends to give yourself a break?

If you answered "yes" to many of these questions, you may need to begin thinking about alternative care options. These are just some of the factors to consider when making this difficult decision. Individual personalities, family history, and outside support should always be a part of your decision. *

Remember, you are doing the best you can and it is alright to ask for help. You need emotional and physical support; a support group is a fantastic resource. Try to plan ahead to prevent

making decisions during a time of crisis. If you, as a caregiver become ill from stress related illnesses, vital decisions may be left to people who do not know your loved one as well as you do.

Once the decision is made that facility care it may be a smoother transition if you are able to plan ahead and visit several facilities to make sure your loved ones needs will be adequately met. It is also important to include the individual with AD in this decision whenever possible. You may obtain a list of facilities in your area by going online to www.medicare.gov and selecting "Nursing Home Compare" or www.aoa.gov or you may call 1-202-619-0724 and ask for a list in your area. The Alzheimer's Association has a new service called Care Finder at www.alz.org under "Care Finder". You may also contact your local Area Office on Aging or State Aging Division and ask for a list. Below are a few tips to consider when looking for a dementia facility:

- **Tour several facilities-**If possible choose several facilities in your area and set up appointments to tour the building. Look for a facility that is designed and committed to care that will help your loved one be successful. Things to look for when touring are:
 - How does the facility smell in general.
 - Do the residents appear clean and happy?
 - How does the staff interact with the residents, visitors and other staff?
 - Is the resident's privacy respected?
 - Does the staff appear happy and content, not stressed?
 - Does the staff address the residents by name and with respect?
- **Tour again-**When you have decided on a couple of facilities, go back and look again-unannounced, perhaps an evening or a week end when there is less management staff. Determine if the atmosphere appears similar to when you toured with a staff member.
- **Environment-**It is important for families to pick a place that resembles the person's home and lifestyle. Does their home feel cozy and lived in or have a more formal and elegant look. A safe environment is just as important, if not more for persons with dementia.
 - How is a safe and secure environment provided for persons with dementia? i.e.: secure doors and gates, safety features in the hallways and bathrooms, lighting.
 - Are there safe areas that allow for independent wandering? Are the residents allowed to use the areas freely?
 - Is there an outdoor area that is safe and secure?
 - How does the environment promote independence? i.e.: cues in the environment that help individuals locate key areas, identify the time of day, a picture of a toilet on the bathroom door.
 - Look for a pleasant dining area.
 - Personal belongings decorating the resident rooms.
 - Residents moving about freely in a safe area
 - Pleasant smells
 - Clutter-free hallways
 - Appropriate noise level that won't cause increased agitation. i.e.: overhead speakers and staff paging, buzzers and bells.
- **Commitment to Alzheimer/dementia care-**Ask staff what is special about the care provided for residents with dementia. Talk to other family members if possible about their experiences with the facility. Look for available information about AD such as brochures, books, etc. A few questions to ask:
 - Will progression of the disease result in transfer or discharge from the program, unit and or/care setting?
 - What is the program's mission and philosophy? Ask to see a copy. *The philosophy should address the unique needs of persons with dementia.*
 - What type of care is provided for persons with late stage dementia?
 - Ask to see a copy of their most recent survey (licensed setting only) that you can read.
 - How the facility views the use of physical and chemical restraint. Restraints will often

cause more problems than they typically solve.

- **Staff qualifications and levels**-Individuals providing care to the person with dementia are an important factor in the quality of care that is received. You will want caregiving staff to not only be kind and friendly, but also skilled and knowledgeable about how to care for someone with dementia.
 - What training does staff receive? *It should include special training in Alzheimer/dementia care.*
 - How often does staff receive training?
 - How many direct care staff are on days? Evenings? Nights? Weekends?
 - How many residents is each direct care staff member responsible for? *This will help you determine how much individual attention your family member will receive.*

- **Activities**-It is important for persons with dementia to receive activity throughout the day that provides pleasure, a sense of usefulness and triggers memories of familiar activities from his/her past. Activities in a facility setting consist of more than just structured group activities. They also include dressing, eating, bathing and spending time alone, if desired.
 - What types of activities are offered?
 - How often are organized activities offered?
 - Are there organized activities during the evening? At night? On the weekend?
 - Where do the activities take place? *They should include inside the facility, outdoors and off grounds if appropriate.*
 - How are activities specifically designed for persons with dementia? *Activities should be individualized and meet the specific needs, interests and abilities of each individual.*
 - Are there television sets on around the area? *People with dementia are often unable to differentiate between television and reality. Television may increase confusion and behaviors.*

- **Look for:**
 - Residents appearing to enjoy the activity
 - Residents doing something that appears meaningful to them
 - Residents sitting in small groups or clusters engaged in some type of stimulation rather than alone in their rooms or grouped around the nurse's station or lounge area and not receiving any type of stimulation.
 - An activity schedule. *If you do not see one, ask to see one, it should be posted in a common area.*

The actual moving day and transition into a facility environment can be a traumatic event for the individual with AD, the caregiver and family members. There are many things that can be done to make the transition as smooth as possible.

Each individual with AD will handle information differently. Some are able to be involved in the decision for placement and will be able to make the transition easily. More often, however, telling the person with AD days or weeks ahead of time will result in the person focusing on the event and having increased anxiety over the move before it happens. Always consider sharing information about the move based on the individual's ability to handle the information without increased anxiety.

Since memory loss is part of the disease process, the transition may take several weeks to become final. Here are a few "moving day" tips to consider:

- **Have the room ready prior to admission.** Decorate the room with some of the individual's personal items, such as pictures, bedding, knick knacks and furniture. Familiar items are comforting and reassuring.

- **Plan to spend the day with your loved one.** Let them help to arrange their room if possible. Walk them to their first meal and stay and eat if possible. Accompany them to some of the activities the first day.
- **Choose the right time of day to move.** People suffering from AD often have a “best time of day”, try to make the move then. Mid-morning hours may work well because more staff is available and there is usually an activity your loved one can attend. Try to avoid “shift change”, there is more activity in the facility at that time.
- **Try to maintain a positive attitude about the move.** Individuals with AD are very perceptive to emotions and body language of those around them. Do your best to not be outwardly upset or fearful, they will pick up on your feelings easily and may become sad and difficult to manage.

Remember that even with the most positive of circumstances, your loved one may intensely dislike the new environment at first. It will take several weeks and sometimes even months for them to finally settle in. The transition period may also be very difficult for the care giver. No one will care for them like you do because you have a long, personal and private relationship with them. You know them; their likes and dislikes. This type of relationship takes time for a facility staff to build with a new resident. There may also be the feelings of sadness, grief and fear of allowing strangers to care for someone you love so deeply. Did I do the right thing? This is a frequent question among the families of new residents in a facility.

Relinquishing day-to-day responsibilities often makes a caregiver feel sad, fearful, guilty and have a sense of loss. These feelings are normal, but do need to be dealt with in order for the transition to occur. A few tips to consider:

- **Plan ahead.** Becoming familiar in advance with the staff at the facility will help you become more comfortable with the facility. Perhaps leave your loved one for some overnight “respite” stays prior to the final move.
- **Define your new caregiver role.** Your role will change (but not end) after admission to a facility. You may want to come in for meals or an activity to do together, such as attending a church service. This can be a difficult change, so stay active and pursue some of your own interests. Enjoying your self and your newly acquired “free” time in no way means that you are abandoning or forgetting your loved one.
- **Talk with others about your feelings and emotions.** Many people will find a support group helpful at this time. Contact any Great Plains Chapter office to find out about the group nearest you or go to www.alzgreatplains.org for a printable list. Or you may spend time getting to know other family members who may be visiting their loved ones. Talking to others who are experiencing similar situations can be extremely helpful.
- **Maintain good communication with the staff.** Share your concerns and suggestions with staff so they can provide a safe and comfortable environment for the individual. You know your loved one better than anyone so offering detailed information will not only help the staff, but also improve the quality of life for the individual with AD. Build a relationship with not only the line staff, but also the supervisors, activity, dietary and management staff.
- **Develop a visitation schedule that is comfortable for you.** At first, you may need some time away to process the change, define your new role and accept the placement. Visit with friends or family members if it is too difficult to visit alone. Encourage other family members to visit with you or at times when you are not able to. This is a good way to involve the family in your loved ones care.