



January: Living Alone with Alzheimer's Disease

A common theme often heard by adult children is asking Mom if she wants to move, but hearing that she wants to stay alone in her own home. The children want to honor Mom and she tells them that the neighbors help her. But, neighbors are calling telling them to do something. Can Mom really stay alone?

Of the 5 million Americans who suffer from dementia, as many as 1.5 million live alone. While families and providers tend to think of dementing illness in terms of memory loss, it is the combination of other symptoms early in the disease that compromise the ability to live alone. The biggest problem occurs before many recognize there is a problem: Executive function.

The person loses the ability to plan things and carry them through in the right sequence to meet a predetermined goal. This results in the loss of ability to perform complex tasks, problems with organizing their day; difficulty with abstract concepts (such as money management); loss of reading comprehension, increasing self-absorption and difficulty in understanding the needs of others.

These losses lead to progressive difficulties with the following functions:

- Paying bills, managing mail and money
- Driving
- Shopping and making good decisions about purchases
- Using the telephone appropriately
- Performing yard work, chores, cleaning, laundry, & cooking
- Participating in religious and social activities
- Initiating hobbies and leisure activities
- Adjusting the thermostat
- Illnesses resulting from medication errors or failing to take medications

Even worse, families report increasing paranoia and resistance to assistance or services. So what is a family to do?

First, as soon as the illness is detected, families need to begin an ongoing discussion about when the time comes that the person can no longer live alone. Ask the question in the abstract: "Mom, if a day comes when you can't live alone, where would you like to go?" If the person has heard the message repeatedly, the need for help may be better accepted. It is important to reinforce that long term care options today are far better than ones the person might have seen a decade ago. Advanced directives with durable powers of attorney must be executed well in advance so the family knows who must make the decision with the person.

Second, try to get the person used to having help in the home as early as possible. Extra in-home support is the best way to prolong the ability to live independently. Be prepared to have the person make tough choices: "Mom, would you rather have cleaning help or live in an assisted living facility (ALF)?" A surprising number of people prefer an ALF to having strangers in their home.

Finally, recognize that living alone is a temporary solution that can actually worsen the person's symptoms. It is best to prepare in advance for the time when living alone is no longer an option. Members of the Family and Community Services team here at BAI are anxious to help families determine the best options for their person and ease transitions when living alone is no longer possible.

The Live Alone Assessment

Professionals can help families make decisions about living situations using what the family reports and supplementing it with other assessments. One of these, the Live-Alone Assessment, is available to families and professionals. It helps families identify problems and prioritizes them by severity. Common problems are listed that are encountered by people with dementia living alone. The family checks off the behaviors/conditions they have observed, such as the person making repeated phone calls or setting the stove ablaze.

Each behavior/condition is assigned a letter "A", "B", or "C." "A" behaviors are emergencies and must be dealt with quickly; "B" behaviors indicate the person is not doing well and will need additional support weeks or months; and "C" behaviors are simply annoying indicating the person should be monitored routinely but there is no need to move them in the foreseeable future. There is also a brief guide to "walk" the caregiver through an in-home assessment, identifying inconsistencies that might indicate problems.

To obtain a copy of the Live-Alone Assessment contact Veronica Ellis at the Family and Community services Program at BAI at veronica.ellis@bannerhealth.com or 602-239-6902.



“Ask the Expert”

By Mary Lou Hernandez, LCSW

Dear Mary Lou

I've gotten the message. My mom needs to move because she can't take care of her house and is relying on the neighbors too much. Do I look for an independent living apartment? An Assisted Living Facility? I know she has memory loss but can't imagine her living in memory care. She says she won't move! What to do?
Signed, “I feel evil!”

Dear Evil

This is a problem encountered by almost every family who has a person with dementia living alone. There are several keys to a successful move. First, start talking about the eventual move early so the person gets used to the idea and can actually participate in planning and finding a new care setting. Subtle questions such as “Mom, if you couldn't live alone, where would you want to live?” can provide a great deal of insight. It is far easier to ask the question in the abstract than try to have the person make a decision during a crisis. It is important not to ask the “Do you want to...?” question as the answer will always be “NO!”

Second, consult with professionals. As a family member it is almost impossible to judge what your member needs. There are no “one size fits all” solutions and each person needs a living situation unique to

their overall needs. A professional (such as the Community and Family Program at BAI, a care consultant at the Alzheimer's Association, a private geriatric care manager or an independent care home locator) can discuss possible care options ranging from in-home care to residential settings, including the associated costs.

Finally, keep an open mind when looking for a place. Remember that you are looking for a place with great supportive staff and lots of activities. Ideally, you are looking for a place your mom can reside for the rest of her life. The fancy furniture and chandeliers are irrelevant when a person is frustrated confused and upset. Allow yourself and your person the luxury of grieving the loss of independence and let professionals help you.

Finally, we expect a person to become upset and somewhat agitated when they move. If the behaviors do not subside in a month it may be that the facility is a poor fit. Do not feel like you have failed. These things happen. Consult with the professionals to resolve these issues, either by finding a new place or using prescription medications to ease the transition.

Mary Lou Hernandez, LCSW is the Social Worker of the Family and Community Services at Banner Alzheimer's Institute.

What's New in the Library

“The complete guide to Alzheimer's Proofing Your Home” (Mark L. Warner, 2000) is a detailed book that shows how to create a home environment that helps you cope with the difficulties associated with dementia. The book covers interior and exterior spaces, discussing both problems and solutions in specific areas such as the kitchen, bathroom, hallways and patios. The book includes examples of over 100 photographs and drawings for simple modifications. There is also an extensive list of resources to help caregivers find the latest products for the home.

Consider checking out this book at the BAI Library or you can purchase it online through Amazon.

“Home Safety for People with Alzheimer's disease” is a free 40-page booklet provided by the National Institutes on Health/National Institute on Aging. (NIH Publication No. 02-5179) You can order or download this online at www.nia.nih.gov/alzheimers. Go to “more publications;” click on “Caregiving/Coping;” and scroll down to “Home Safety.” This publication is also available in Spanish.

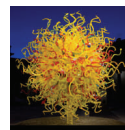
Beacon Bits

Memory Assistance & Planning Service (MAPS) for Care Partners now available in two different formats!

COMPASS (Caregivers Of Memory impaired Persons Acquiring Successful Strategies) is a 90-minute introduction into caregiving for Alzheimer's disease/dementia. This class will be held on Thursday, January 22nd from 10-11:30am in the BAI 3rd Floor Conference Room.

MAPS is a 2-day program that provides in-depth information and strategies for caregiving. Join us February 7th and 21st at Banner Estrella Medical Center, Conference Room 2 (see insert) **Call Veronica Ellis @ 602-239-6850 to register!**

BAI Explorer Outings!



Chihuly: the Nature of Glass tour & visit at the Desert Botanical Garden. Held on January 16, 2009 Friday at 9:30 AM—11:00 AM. Enjoy a tour of the Chihuly's spectacular glass creations. Dale Chihuly is well known for his innovative glass structures that have been on display over 200 museums around the world. The tour costs \$20.00 per person. **Please call Veronica Ellis to register at 602-239-6850**

Our Mission

To end Alzheimer's disease without losing a generation, to set a new standard of care for patients and their families, and to forge a model of collaboration in biomedical research.