



When home is no longer working: How to handle the care transition

With Alzheimer's disease or a related dementia, care needs increase as the condition progresses. Although staying at home is ideal, many people will need to consider a different living situation that provides more support and structure at some stage of their dementia. There are many variables that affect this decision as each person has a different support network and living situation. The time of a transition will also vary based upon caregiver abilities and care needs. There is no doubt that considering a move to a residential care setting can be very stressful and emotional for all involved. Proactive planning to look ahead for options before they are needed is an ideal strategy. It is important to have a future plan for care in place or options to meet care needs in case of an unexpected situation.

There are a variety of situations that may warrant a move to a residential care setting:

- A person with dementia that is living alone will not be able to remain unassisted and a move is necessary when certain risk factors are observed. Safety concerns to be aware of include not taking medications, losing weight due to not eating, burning items on the stove, having spoiled food in the refrigerator, and/or opening the door to strangers. Difficulty managing household chores such as cooking, cleaning and finances that are worsening. The person may become withdrawn and isolated, especially if driving has stopped. The person with dementia may want to move if they feel fearful or overwhelmed with daily tasks.
- A person living with a spouse or family member that works full time and is not safe to be left at home alone.

- Physical care needs increase which may be too difficult for a spouse or family member to manage including bowel or bladder accidents, assistance with bathing and personal care, decreased mobility, frequent falls, and/or limited communication.
- If the person with dementia becomes resistant to care or becomes physically aggressive and more difficult to assist.
- A spouse or family caregiver may become physically or emotionally exhausted, increasingly fragile or experience a terminal illness.
- A couple wants to transition to a retirement community with progressive levels of care so they can remain together in the same setting as the care needs of the person with dementia increase.
- Occasionally the spouse who is the primary caregiver of a person with dementia begins to have a cognitive impairment, so the couple both need a structured, supervised setting with daily assistance.

There are different residential settings that are licensed in Arizona to provide care for people with dementia. Memory care assisted living centers are specialized facilities or units that provide dementia care exclusively. These may be free standing centers or part of a larger retirement community that has progressive levels of care. Other options include adult care homes which are private residences that care for 10 or less residents. Skilled nursing facilities may also have a dementia unit for people who have complex medical needs in addition to their dementia. Arizona State licensing evaluations for all of these settings can be reviewed at www.azcarecheck.com.

It is necessary to be aware of how a residential care setting will be paid for when considering a move. Medicare is not an option to cover long term care needs in a residential setting. Medicare only covers very specific skilled needs in a skilled nursing facility for a limited amount of time and usually requires a person to be hospitalized first. If there is long term care insurance, be sure to read the policy to determine the specifics of coverage and activate it at the appropriate time to help cover these expenses. The VA Aid & Attendance program may be another option to investigate for veterans who served during a period of war or for their surviving spouses. A helpful website to learn about this is www.veteranaid.org. In many cases, private pay for a residential care setting will be necessary initially. Once assets are reduced or spent down, Arizona's Medicaid program can be applied for. This program is called Arizona Long Term Care or "ALTCS." With ALTCS, there is a spousal protection for half of the couple's shared assets. This preserves up to \$120,900 for the well spouse. More information on paying for care can be obtained by attending the Planning Ahead class through Banner Alzheimer's Institute or viewing this on line at <http://www.banneralz.org/education-events/online-education.aspx>.

If a transition to a residential care center is anticipated in the future, it is helpful to begin visiting centers in advance and when there is less stress or pressure to make an immediate decision. Caregivers need to feel secure and comfortable with their decision. Visit several centers or adult care homes to compare and contrast. Have a checklist of questions to ask at each center/home. Consider locations close to home or family for convenient visitation. When choices are narrowed down, return at various times of the day to observe the atmosphere and activities. Review activities offered that will match your person's likes and interests. Ask questions about the staff and if they have had dementia training. Do the other residents appear engaged and happy? All of these considerations may be more important than the décor. Have other family members visit for their thoughts and feedback. Be sure to take notes and write your observations down to refer to when making a final decision. If a center is preferred, determine how often they have openings as it may be helpful to have your person placed on a waiting list.

It is important to be cautious about involving the person with dementia in planning for a move and visiting residential care settings. If the person is in the mild stage and wants to move, it may be helpful to involve them. However, narrowing the search to the best few centers for them to visit is preferable than taking them to see all options available. The goal is for the person not to feel overwhelmed or stressed about making a transition. If the person is resistant to the move or in the moderate stage, it is best to plan a move without their involvement. Discussing options or the need to move may only increase their anxiety and/or resistance. The person may not understand the benefits of planning ahead. Once a center is decided upon, your person can be taken there for lunch or a visit without extensive explanations about the plan. The purpose is to give them some familiarity with the setting. In the advanced stage, the person lacks the decision making abilities so should not be involved at all.

The next step is preparing for and considering when to make a move if a center has been chosen. Sometimes a crisis or emergency will expedite the plan. This can occur if the person with dementia is hospitalized and cannot return to living at home alone or if care is too much for the family caregiver. If the primary caregiver becomes sick or dies, an immediate move for the person with dementia will be necessary. Finally, a critical safety concern may hasten a move to a residential care setting such as overdosing on or not taking medications, weight loss due to not eating, becoming lost or having an accident when driving, wandering away from home, or sudden behavior changes.

If the person with dementia is involved and agreeable with the move to a residential care setting, be aware that change can be overwhelming and increase anxiety. Caregivers need to be mindful of this and allow the person to verbalize their feelings while providing reassurance and support. Speak about the move closer to the time of the transition and be positive about the change. The more advanced the person is with their dementia, the less discussion there should be about the move.

If the person with dementia is resistant to moving to a residential care setting, caregivers may need to find creative ways to handle this transition. Some examples are as follows:

- The well spouse needs more care, therefore the spouse with dementia must accompany them.
- The move was ordered by the doctor.
- There is a problem with the house which needs to be vacated to fix it.
- The person with dementia needs therapy or "special care".
- The move is temporary to "test" the setting.
- Family members/children make the decision.
- This is a step down from a hospitalization or emergency room visit as ordered by the doctor for discharge planning.

Packing or downsizing in preparation for the move can result in anxiety and increased stress. If the person with dementia is involved with packing, be realistic about what they can accomplish and for how long they can engage in this task. Pack for a short time followed by a rest period. Be aware that decision making is more impaired so it may be difficult for the person to decide what to bring. Have them decide about the most important items and sort the remainder when they are not present. Consider having a moving company pack and unpack their items. If the person with dementia is not aware of the move, packing may need to occur on the day of the transition or after.

At the residential care center, have the room or apartment ready with familiar items to help the person with dementia feel comfortable. Be cautious about bringing valuables. Starting a calming medication several days before the move can help ease anxiety about the transition. Tell the staff at the residential care facility about the person with dementia for increased familiarity. Discuss their likes, dislikes, medical conditions, temperament, habits and **who they are**. The more the staff knows about the person, the easier it will be for them to help with the adjustment.

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.

It is very important to be aware of and validate emotions regarding the transition to a new living situation. For the person with dementia, change in residence and familiar surroundings can result in anxiety, stress and fear of the unknown. Change in their sense of independence can result in feelings of grief and loss. Leaving a home and surroundings which have memories and possessions with sentimental value can result in anger or sadness. On the other hand, decreased responsibilities and services available can provide a sense of relief and safety. Caregivers may feel guilt or sadness due to loss of this role. Family discord can occur if some family members do not agree with the move or when there is unequal distribution of responsibilities. Be aware that if the family is emotional about the change, the person with dementia may react to this. The goal is to be calm and positive with them about the move. In many cases, the anticipation of planning for a move is more stressful for the family than the actual move for the person with dementia.

— continued on back panel



Ask The Expert

Mary Lou Hernandez, LCSW, MSW
Social Worker, Stead Family Memory Center

Families frequently request what they should ask and look for when visiting a residential care setting. Here are the core group of questions I recommend. Take good notes so when you go home, you are able to compare your choices.

Core philosophy

- Does the facility have different levels of care as the resident's care needs increase?
- Can hospice care be delivered here allowing the resident not to move?
- What are the visiting hours?
- What are expectations for family involvement?

Living space

- Can the resident bring their own furniture?
- Can the resident bring a pet?
- Is the temperature comfortable for the residents?
- Are the noise levels in the dining room and common areas comfortable for residents?
- What type of food selections are there?
- Are snacks readily available?

Staff

- Does the relationship between the staff and residents appear to be warm, polite and respectful?
- What is the resident to staff ratio?
- Do the caregivers receive specific training on how to care for residents with Alzheimer's/ related dementia? How much/how often?
- How does the staff get to know about the resident's life history and personalize care for the resident?
- How does the staff work with families to assist with the transition to the facility?
- Does the facility have a doctor?
- Can the resident keep their own doctor?

Activities

- What type of activities does the facility have?
- How do the caregivers engage the resident in activities?
- Are there outside areas where the resident can walk freely?

Financial

- Does the facility have an ALTCS contract?
- If so, what plans do they accept?



www.banneralz.org
602.839.6900

A charitable bequest is a wonderful way for you to help further the work of Banner Alzheimer's Foundation and its mission of delivering care and hope to families while advancing research. To learn more, please contact us at (602) 747-GIVE (4483) or plannedgiving@bannerhealth.com

Have a Question?

To submit your question for future consideration email us at: baiinfo@bannerhealth.com





Banner Health®

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— continued from inside

Be sure that a family member or caregiver is present during and after the move to help with the adjustment. Reassure the person with dementia that they will be cared for and family will be back to visit. Visit on a daily basis for short periods of time. When it is time to leave, coordinate this with a meal or an activity to distract the person and quietly slip away. Try to minimize emotional goodbyes. When visiting, bring a special treat or activity. Ask the staff at the residence to keep a closer watch over your person as the extra attention and support can help with the transition. Having a positive relationship with the staff will transfer over to the resident. Focus on what the staff is doing well rather than only criticism.

Expect an adjustment period for the person with dementia after the move. They have to become familiar with a new routine, environment and people. This can result in feelings of frustration and irritability. The person with dementia may be angry and agitated about the move. Allow them to grieve and express their feelings. Slowly engage them with other residents or pleasurable activities that they may enjoy. Be cautious about taking the person out of the center for the first month as they may be confused or reluctant to return. It will take some time to learn a new daily routine; but with time, they will adapt to the new setting.

Family caregivers will continue to be an advocate for the person with dementia in this new setting. Roles will change as responsibilities change. Caregivers may return to being the



husband, wife, son, daughter, partner or friend. This can be a major emotional change for the caregiver who now may be living apart from the person with dementia. It is important to have a source for emotional support to discuss these feelings and provide coping strategies. Support groups and peer interactions in addition to professional counselors are ideal resources. Caregivers need to continue caring for themselves!

In summary, it is always beneficial to have a backup plan for when more care may be needed for a person with dementia. Planning ahead can reduce the stress of a move and help families be prepared for when a residential care setting is needed. To learn more about when home is no longer working, join our Dementia Dialogue webinar on March 15 from 12N-1P. Register at www.banneralz.org/dementiadialogues.



CAREGIVER EDUCATION PROGRAM SCHEDULE

March/April 2017

MARCH

Finding Meaning While Living with Loss

Caring for someone with dementia creates ongoing awareness of loss as the person with dementia is physically present but psychologically different from who they once were. This can be confusing and overwhelming for family and others who care about them. This class provides strategies to infuse hope and meaning into one's life while providing care in order to cope with continual changes. ****Also available to view online at www.banneralz.org (see online education - December 2016 Dementia Dialogue Webinar).**

Thurs., March 2; 1:00 - 2:30 p.m.

BAI, 901 E. Willetta Street, Phoenix

To register, call (602) 839-6850

AND

Wed., March 15; 2:00 - 3:30 p.m.

BSHRI, 10515 W. Santa Fe Dr., Sun City

To register, call (623) 832-3248

Dementia Friendly Tempe Presents: Help at Home: Support for the person living at home

There are many options available when additional care is needed. However, it is often overwhelming to know where to begin and how to find the right fit for you and your person. This session will review possible options for care in and out of home; how to make an informed decision and ensure success.

Wed., March 8; 1:00 - 2:30 p.m.

Tempe Public Library

3500 S. Rural Road, Tempe

AND

Mon., March 27; 4:00 - 5:30 p.m.

BAI, 901 E. Willetta Street, Phoenix

To register for both locations, call

(602) 839-6850

Dementia Dialogue Webinar: When Home is No Longer Working: How to Handle the Care Transition

Most families want to keep their person with dementia at home as long as possible. As the disease and care needs progress, residential care may be an essential next step. This Dialogue explores common triggers to a transition in care and what you can do to

minimize the stress of this change.

Wed., March 15; Noon - 1:00 p.m.

(AZ Time). Each webinar/teleconference meets on 3rd Wednesday of each month from 12N - 1pm AZ time. To register, visit www.banneralz.org/dementiadialogues or call 623-832-3248.

Denial: Understanding Why Your Person Doesn't Understand

Families often think their person is in denial about their dementia diagnosis. However, some people with the disease are unable to see changes in themselves. This 60-minute class will assist participants to learn the difference between denial and lack of insight providing strategies to avoid confrontation.

****Also available for viewing online at www.banneralz.org (see online education - February 2015 Dementia Dialogue Webinar).**

Tues., March 28; 1:00 - 2:30 p.m.

BSHRI, 10515 W. Santa Fe Dr., Sun City

To register, call (623) 832-3248

APRIL

As Dementia Progresses: Next Steps for Caregivers

This class helps caregivers to understand the moderate to advanced stages of Alzheimer's disease/related dementia. Caregivers will learn about expected changes in memory, thinking, mood, behavior and function.

Practical strategies are provided to assist caregivers to find success in their efforts.

****Also available for DVD purchase or free viewing online at www.banneralz.org (see online education).**

Tues., April 4; 10:00 - Noon

BAI, 901 E. Willetta St., Phoenix

To register, call (602) 839-6850

Dementia Friendly Tempe Presents: My Favorite Apps for People with Memory Loss

Family members often struggle to think of ways to keep the person with memory loss occupied during the day. iPads and tablets provide numerous opportunities to keep the person with memory loss engaged in fun and successful activities when the right apps are used! Bring your iPad, iPhone or tablet to this interactive class. Nick Escalante, Senior

Services Coordinator with the Tempe Public Library, will help you find the apps that are right for your person!

Wed., April 12; 1:00 - 2:30 p.m.

Tempe Public Library

3500 S. Rural Road, Tempe

To register, call (602) 839-6850

Residential Care: When moving becomes the best option

Transitioning from home to a residential care setting can be challenging for caregivers and the person with dementia. This class will discuss the importance of planning and considerations when making the transition from one level of care to another.

Mon., April 17; 4:00 - 5:30 p.m.

BAI, 901 E. Willetta Street, Phoenix

To register, call (602) 839-6850

Dementia Dialogue Webinar Series: Managing the Negative Emotions from Caregiving

Caregivers often voice feelings of sadness, frustration and anger that can lead to guilt. These feelings are normal and result from the demands of an unrelenting role. This Dialogue explores how caregivers can effectively manage their emotions so they don't get the best of you.

Wed., April 19; Noon - 1:00 p.m.

(AZ Time). Each webinar/teleconference meets

on 3rd Wednesday of each month from 12N -

1pm AZ time. To register, visit www.banneralz.org/dementiadialogues or call 623-832-3248.

Learning to Provide Hands on Care: A skills lab for family caregivers

This skills lab will allow caregivers to learn how to provide personal care (grooming, oral care, bathing, dressing), manage incontinence, adapt to changes in eating, move the person in/out of a chair and bed, and identify medical equipment for home use.

Fri., April 21; 10:00 a.m. - 12:30 p.m.

Foundation for Senior Living Caregiver House

1201 E. Thomas Road, Phoenix

To register, call (602) 839-6850

Financial Assistance:

Understanding ALTCS & VA Benefits

There are options to assist patients and families to offset the cost of long term care for those who qualify. This class will dispel common myths while reviewing eligibility criteria and steps needed to apply.

Wed., April 26; 10:30 – 11:30 a.m. (ALTCS) and 11:30 a.m. – 12:30 p.m. (VA Benefits)

Pyle Adult Recreation Center
655 E. Southern Ave., Tempe
To register, call (602) 839-6850

MULTIPLE MONTH CLASSES

Travel: Planning for Success

Travel can still be enjoyable for someone with dementia but extra time, effort and planning is required. This class will provide methods for how to make trips as successful as possible. ****Also available for viewing online at www.banneralz.org (see online education – May 2015 Dementia Dialogue Webinar).**

Thurs., March 2; 10:00 – 11:30 a.m.

BAI, 901 E. Willetta Street, Phoenix
To register, call (602) 839-6850
AND

Tues., April 11; 1:00 – 2:30 p.m.

BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (623) 832-3248

Activities: Filling the Day with Meaning and Purpose

Keeping people with dementia engaged and mentally stimulated is a common concern for caregivers. This class will discuss how to adapt activities as the disease progresses and how to find a variety of stimulating and engaging activities that work in order for the person to have fun and find success.

Mon., March 13; 10:00 – 11:30 a.m.

BAI, 901 E. Willetta Street, Phoenix
To register, call (602) 839-6850
AND

Tues., March 21; 10:00 – 11:30 a.m.

Mesa Red Mountain Library
635 N. Power Road, Mesa
AND

Wed., April 19; 10:00 – 11:30 a.m.

BSHRI 10515 W. Santa Fe Dr., Morin, Sun City
To register, call (623) 832-3248

Planning Ahead Class for Caregivers

Alzheimer's disease/dementia is a condition that can last for 8 – 10 years and WILL require additional help and care as the condition changes. Caregivers will learn about medical, legal and financial decisions that are needed along with how to find help and pay for care in the home, community and residential settings. ****Also available for DVD purchase or free viewing online at www.banneralz.org (see online education)**

Tues., March 14; 4:00 – 6:00 p.m.

Tues., April 11; 10:00 a.m. – Noon

BAI, 901 E. Willetta St., Phoenix
To register, call (602) 839-6850

Behaviors: Expressing What Words Cannot

Dementia affects the ability to manage emotions, carry out daily living tasks, navigate the environment and communicate in a logical way. Therefore “behaviors” communicate a real sense of discomfort for the both the person with dementia and caregiver. This class will address the most common types of behavior problems and pose a variety of solutions that caregivers can easily utilize.

Thurs., March 30; 10:00 – 11:30 a.m.

BAI, 901 E. Willetta St., Phoenix
AND

Tues., April 18; 10:00 – 11:30 a.m.

Mesa Red Mountain Library
635 N. Power Road, Mesa
To register for both locations, call (602) 839-6850

Directions for Caregivers After the Dementia Diagnosis

This class reviews the basics of dementia from the various types to progression and treatments available. Most importantly, caregivers will learn the 8 most essential strategies to avoid many of the unwanted behaviors that arise due to the demands of the illness.

Thurs., March 23; 10:00 – 11:30 a.m.

Mon., April 10; 4:00 – 5:30 p.m.

BAI, 901 E. Willetta Street, Phoenix
To register, call (602) 839-6850
AND

Wed., March 1; 10:00 – 11:30 a.m.

Fri., March 24; 1:00 – 2:30 p.m.

Wed., April 5; 10:00 – 11:30 a.m.

BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (623) 832-3248

Banner Brain Health Program

Learn how lifestyle choices can minimize the risk of Alzheimer's disease and then “flex” your cognitive muscles as you determine how to exercise your brain! This class teaches and provides tips for healthy adults how to use certain activities to help improve cognition, memory and recall. ****Cognitively Normal Adults.**

Wed., March 29; 1:00 – 3:30 p.m.

Wed., April 12; 1:00 – 3:30 p.m.

BAI, 901 E. Willetta St., Phoenix
AND

Wed., March 22; 10:00 a.m. – 12:30 p.m.

BSHRI, 10515 W. Santa Fe Dr., Sun City

To register for both locations, call (602) 230-CARE (2273)

All classes are
free,* but registration
is required.
(*unless noted)

To learn about upcoming education and support programs dates at:

- Banner Alzheimer's Institute, visit www.banneralz.org and click on “Events Calendar” icon or call Deidra Colvin, Events Coordinator at 602-839-6850
- Banner Sun Health Research Institute, visit www.bannershri.org and click on “Events and Education” or call Veronica Flores, Events Coordinator at 623-832-3248

These programs are made possible
by the generous support of the
Banner Alzheimer's Foundation.



Banner Alzheimer's Institute
Banner Sun Health Research Institute