



How Do I Advocate for My Person with Dementia Now That She Lives in a Residential Facility?

You as an advocate

You've spent several years caring for your person with dementia. Little by little you developed as a care partner into a caregiver. You've learned how to adapt daily routines, find resources, assist with complicated activities such as managing finances, seeking medical care, finding activities, and promoting safety. You did all this while also assuming the responsibility for telling and keeping your person's story. You are a savvy caregiver, however, you have been developing another skill. You have become your person's advocate.

Becoming an advocate generally happens naturally, often without a lot of discussion. An advocate pleads the cause of another, publically recommends support, and/or defends or maintains a cause. Advocacy is not clearly defined or static, rather it changes in character and intensity as needs arise. This may occur without the knowledge of your person or even formally, such as being identified as the person's durable power of attorney. If

you have become a caregiver, you have also become your person's advocate, making decisions with or for them.

Decision making and advocacy is much easier when your person lives with you or in their own home. But as the dementia progresses into the moderate or advanced stages, many caregivers find they need additional help and even residential care for their person. This can bring about new challenges as it can be complicated. Residential care facilities have rules, regulation, staff, and other residents. All of these confound your role and power as your person's advocate. For example, if you want to bring in extra food or a special activity, it may interfere with dietary or safety rules for other residents. Bringing in a television, music, or a pet for your person may interfere with the needs of a roommate. Or, you may find the facility's ideas about dementia care conflict with yours. There may be limits on visiting your person during the first weeks of placement. These rules and restrictions can increase your stress and result in multiple moves for your person (and you!).

Adapting your role to a residential facility

Prior to placement, it is important to recognize that you are the most important person in your loved one's life. Facilities have to consider the needs of all residents; whereas your job is to advocate only for your person. Therefore when visiting potential facilities, you need to listen for clues that demonstrate their concern for both your person and you. Suggestions such as discouraging visiting early in the placement may not serve you or your person well. In fact, this might increase anxiety for both of you. During facility interviews continuously ask yourself, "Do I feel I can work with the staff and administrators?" Ask a few questions about how your person's special needs might be met. Ask to meet the administrator, social worker, or director of nursing. If they are not available to meet, offer to come back for another appointment. Your comfort with the facility staff is far more important than the décor. Make decisions considering what your person would want balanced with what you need from the facility.

Sometimes you need an advocate for you! It may be overwhelming to know where to start to find the best residential setting. Help is available through multiple sources. Consider contacting the Area Agency on Aging (www.n4a.org) for your area or the Alzheimer's Association (www.alz.org) as both organizations have knowledge about residential care. You may want to use a placement service to help you find the right place. Keep in mind that some placement agencies will charge you for this service while others are paid by the residential setting for the referral. Ask friends or support group members who have used care facilities for their suggestions. All of these can be invaluable resources for finding care.

After admission

It is essential that you help the new care team learn about your person as this will ensure the best care possible. Help them to know your person's life story. This includes: preferred name, important people in your person's life, favorite foods, activities, TV shows, music, routines that bring comfort, bathing preferences, etc. Let them know how to approach your person, what behavioral expressions mean and how to minimize them. Now is a time when your role as an advocate is needed – helping your person to adjust while assisting the staff to know how to care for your person. This takes time, patience and sharing what you've learned over the years. Don't expect them to get it right immediately. With your guidance, they will get there.

Be aware that it is not uncommon about 48 hours after admission for individuals to become agitated. This is called "relocation trauma" and it can last several weeks. Contact the person's doctor a week or so prior to admission and ask for medications to prevent or treat the agitation. That way you can oversee the medications used and advocate for the lowest possible doses. However, let the staff know how they can use distractions to keep your person more comfortable. Things like favorite treats, talking about familiar stories or using music are examples that you might provide to staff to try with your person.

When problems arise

Ask the administrative staff how they prefer to manage feedback and/or criticisms: who you speak with; whether you need an appointment; whether you should speak with direct care staff; and when to meet. Never try to discipline a hands-on caregiver. Know the chain of command and use it. Many facilities provide a family/resident counsel or support group. Plan to attend meetings and participate in the discussion. Do more than complain. Report when you see good things happen. You know how tough this job can be and how good it feels to be told that you are a good caregiver. Direct care staff need this feedback too!

Do not threaten the staff with lawsuits. That makes it impossible to provide care for your person and will result in adversarial relationships. It may even result in discharge. There is no such thing as perfect dementia care, only people trying their best.

Missing stuff

Be careful to avoid blame. Residential facilities serving confused adults always have problems with lost garments and room decorations. A few tips:

- Do not bring in a large selection of designer clothing. Keep the clothing simple with a small number of garments. Place iron-on labels in your person's clothing and even offer to do their laundry if that is important to you.
- If a piece of clothing is missing don't panic! It is probably being worn by another confused resident. Remember that young care staff do not want clothing for an elderly confused person.
- Take all valuable jewelry home. Consider imposter jewelry instead. You can also ask the jeweler to create jewelry using imitation stones if needed.

Gifts anyone can afford

Have you ever wished you could help but thought you couldn't afford to give? There is good news! You can support Banner Alzheimer's Foundation without impacting yourself or your family. To learn more, please contact us at 602.747.GIVE (4483) or plannedgiving@bannerhealth.com.



Ask The Expert

Geri Hall, PhD, GCS, FAAN
Clinical Nurse Specialist

Dear Geri,

I fear I've made a terrible mistake. I've cared for my dad in his home for years but now he can't manage on his own. He refused to let me hire caregivers and demanded that I leave my husband and three young children to come to live with him. My spouse and I work full time and with our family responsibilities I didn't feel I could do that. I felt so guilty...

I searched our area and found a beautiful care facility. It has wonderful furnishings, a garden, grand piano and several levels of care should dad's condition worsen. Five weeks ago we admitted him to an independent living apartment. Things have not gone well. Dad says he hates it there. He gets lost trying to find his room and is not making friends with the other residents - who try to avoid him. He is missing meals and spending all of his time in his room. When I call he is angry, confused, and thinks the staff is "out to get him." He isn't bathing or changing clothes - says he doesn't need any help. He refuses to go to activities with "those old people."

Yesterday afternoon the administrator stopped by and suggested Dad needs memory care. That would cost more and is not nearly as nice as where he is now. I think they want to "dump" him. Where did we go wrong? What can we do to make Dad happy in this lovely place?

Signed,
Elaine

Dear Elaine,

No need to feel guilty. Your dilemma is one of the most common mistakes caregivers make when confronted with the need for residential care: overestimating the person's abilities. When you visited, your dad looked good and reported to you and the facility that he was functioning well while living alone. When determining how much assistance is needed families often overlook the tiny essential cues, directions, and assistance they provide. You probably thought "Well, he COULD do it if he had to." And you probably thought an apartment would be easier for him than his home. You probably thought that neighbors would make friends and help him to find the dining room at mealtimes. Unfortunately, the new resident with dementia is rarely greeted enthusiastically by other non-impaired residents.

Change of location is particularly difficult for people with dementia, especially when moving to a facility where everything is new and strange. Independent living units are designed for people who are oriented, can tell time, initiate activity, and develop social interactions. So, we see the resident become increasingly disabled and agitated due to the demands of the environment. We call this "relocation trauma." We expect it to start a day or two after the move and last a few weeks.

The answer to this problem is relatively simple. Dad needs a higher level of care where there are staff to help to cue him for meals, grooming, and activities. He needs to be with residents who have similar cognitive abilities and where activities provide the structure for interaction. In short, Dad needs the assisted living level of care. Yes, it is much more expensive but he will get the support he needs now and in the future to be comfortable, safe and happy. You took an important first step. The next will hopefully help your dad to settle into his new home.



www.banneralz.org
602.839.6900

Sentiments and Situations Group is a new support group to help caregivers to share and problem-solve difficult situations and feelings related to caregiving and dementia. In July we will discuss advocating for your person's needs in residential care. Please join us on Thursday, July 13, 2017 from 12:30 – 2:00pm at Banner Alzheimer's Institute, 901 E. Willetta St., Phoenix, First Floor Education Center.

Dementia Dialogue Webinar: Advocating for my Person's Needs in Residential Care.

Join the discussion on Wednesday, July 19, 2017, 12N – 1pm (AZ time). Registration required: www.banneralz.org/dementialogues. If you need to register for audio only, call 623.832.3248.

A tree provides enough oxygen for three people to breath. Please assist us in our Go Green campaign and consider receiving our new and improved online BAI Beacon Newsletter version. Please email us at bannerresearch@bannerhealth.com with feedback or to refer others who wish to receive this web version.

Please help us expand our viewership. If you enjoyed the article, please free to share the link with family, friends and on social media.

Have a Question?

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





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Banner Sun Health Research Institute

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Phoenix, AZ 85006

How Do I Advocate for My Person with Dementia Now that She Lives in a Residential Facility? (con't)

- If your person has removable dentures ask the staff to examine the person's napkin before taking the tray. Resident's often wrap dentures and hearing aids in dinner napkins.
- Remind the staff that glasses, hearing aids and dentures are important to your person's well-being and that you appreciate their careful attention to these items.

Building your care team

You are now part of your person's care team and getting to know them is essential. Introduce yourself to them and let them know how you'd like to be addressed. Ask care and medical staff how they would like to be addressed by you as this shows mutual respect for the roles they play. If you want to participate in your person's care, let them know how and when you'd like to participate. Make a point of finding the staff doing something well and mention it to them - often. They are more likely to accept your negative feedback if most of the time you are positive. Always remember your caregiving experience and how difficult it was a times. The hands-on care providers have similar experiences as they care for multiple people with dementia.

Over a period of days ask how the direct care staff like things done and the usual facility routine. Suggest ways that this can be coordinated with your person's preferences/needs and their routines as well.

Visit frequently over the first few weeks so the staff gets to know you and your person. Take something with you to do such as brushing hair, reading a letter, food to share or participate in an activity together. Try to end the visit immediately before a meal so the staff can help you leave without causing upset for your person.

Over time

Keep your sense of humor and stay involved if you are able. Dementia care can be difficult but very engaging if you're open to the possibilities. Devise ways of thanking staff for their attention and care. Over time you may find you become part of the facility "family," coming to know and care about other residents and staff. We hope that advocating for your person is as rewarding in the facility as it was at home. You matter to your person right to the end.



CAREGIVER EDUCATION PROGRAM SCHEDULE

July/August 2017

July

Date	Time	Name of Class	Location	To Register
July 7, Fri.	1:00pm – 2:30pm	Finding Meaning while Living with Loss	BSHRI	623.832.3248
July 11, Tues.	2:00pm – 3:30pm	After the Dementia Diagnosis (formerly COMPASS)	BSHRI	623.832.3248
July 11, Tues.	4:00pm – 6:00pm	Planning Ahead Class for Caregivers	BAI	602.839.6850
July 12, Wed.	1:00pm – 2:30pm	Dementia Friendly Tempe Presents: Become a Dementia Friend!	Tempe Public Library	602.839.6850
July 17, Mon.	10:00am – 11:30am	After the Dementia Diagnosis (formerly COMPASS)	BAI	602.839.6850
July 18, Tues.	10:00am – Noon	As Dementia Progresses: Next Steps for Caregivers	Mesa Red Mountain Library	602.839.6850
July 19, Wed.	Noon – 1:00pm (AZ Time)	Dementia Dialogues Webinar Series: How Can I Advocate for my Person's Needs when He no Longer Lives at Home?	Online	www.banneralz.org under events/education
BSHRI Same Day Sessions – must register for each session individually				
July 19, Wed.	1:30pm – 2:30pm	Session 1 – Understanding ALTCS	BSHRI	623.832.3248
July 19, Wed.	3:00pm – 4:00pm	Session 2 – VA Benefits	BSHRI	623.832.3248
July 20, Thurs.	10:00am – 11:30am	Behaviors: Expressing What Words Cannot	BAI	602.839.6850
July 21, Fri.	9:00am – Noon	Free Memory Screening	BAI	602.839.6850
July 24, Mon.	9:30am – Noon	Banner Brain Health Program	BAI	602.230.CARE (2273)
July 26, Wed.	9:30am – Noon	Banner Brain Health Program	BSHRI	602.230.CARE (2273)
July 27, Thurs.	10:00am – Noon	As Dementia Progresses: Next Steps for Caregivers	BAI	602.839.6850
July 28, Fri.	1:00pm – 2:30pm	Communication: Avoiding Arguments	BSHRI	623.832.3248

Banner Alzheimer's Institute (BAI Downtown Phoenix)
901 E. Willetta Street, Phoenix
Register at: 602.839.6850

Banner Sun Health Research Institute (BSHRI Sun City)
10515 W. Santa Fe, Sun City
Register at: 623.832.3248

Tempe Public Library
3500 S. Rural Road, Tempe
Register at: 602.839.6850

Mesa Red Mountain Library
635 N. Power Road, Mesa
Register at: 602.839.6850

Dementia Dialogues Webinar Series
Register at: www.banneralz.org/dementialogues
Please note that all webinars are recorded and archived on website 24-28 hours after live session or call 623.832.3248



August

Date	Time	Name of Class	Location	To Register
Aug. 2, Wed.	10:30am- Noon	Planning Ahead Class for Caregivers	BSHRI	623.832.3248
Aug. 4, Fri.	2:00pm – 3:30pm	Good News in Alzheimer’s disease Research	BSHRI	623.832.3248
Aug. 8, Tues.	1:00pm – 2:30pm	Behaviors: Expressing What Words Cannot	BSHRI	623.832.3248
Aug. 9, Wed.	1:00pm – 2:30pm	Dementia Friendly Tempe Presents: Become a Dementia Friend!	Tempe Public Library	602.839.6850
Aug. 11, Fri.	9:30am – Noon	Banner Brain Health Program	BAI	602.230.CARE (2273)
Aug. 15, Tues.	10:00am – 11:30am	Emotional Impact of Living with Alzheimer’s disease	Mesa Red Mountain Library	602.839.6850
Aug. 16, Wed.	9:00am – 10:30am	Emotional Changes: Understanding Symptoms Beyond Memory Loss	BSHRI	623.832.3248
Aug. 16, Wed.	Noon – 1:00pm (AZ Time)	Dementia Dialogues Webinar Series: Helping the Person with Dementia Feel Worthwhile	Online	www.banneralz.org under events/education
Aug. 17, Thurs.	10:00am – 11:30am	After the Dementia Diagnosis (formerly COMPASS)	BAI	602.839.6850
Aug. 22, Tues.	10:00am – 11:30am	Communication: Avoiding Arguments	BAI	602.839.6850
Aug. 23, Wed.	2:00pm – 4:00pm	Planning Ahead Class for Caregivers	BAI	602.839.6850
Aug. 24, Thurs.	10:00am – 11:30am	Finding Meaning While Living with Loss	BAI	602.839.6850
Aug. 29, Tues.	2:00pm – 3:30pm	Denial: Understanding Why your Person Doesn’t Understand	BSHRI	623.832.3248

Banner Alzheimer’s Institute (BAI Downtown Phoenix)
901 E. Willetta Street, Phoenix
Register at: 602.839.6850

Banner Sun Health Research Institute (BSHRI Sun City)
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Tempe Public Library
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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 calendar 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