



Family Conflict: Weddings, Funerals and Dementia

With some 15-20 million American family members involved in some capacity in the care of a person with dementia, it stands to reason that family conflict will arise at some point along the way. Unfortunately, Alzheimer's disease (AD)/related dementias leads to progressive and unexpected changes in the affected person. This results in the person often being very different than in the past; and this in turn can upset the balance within a family. Subsequently old family issues, pre-existing tensions, challenging family dynamics (including blended families) are likely to resurface. These tensions can escalate when decisions need to be made about the person with dementia such as the living situation, driving, ongoing care, etc. Emotions run high with this added stress, particularly when family members each share a unique relationship to the affected person, are tired, stressed and often understand the situation very differently. This article will outline some of the common family conflicts and situations encountered while providing possible solutions to keeping the needs of the person with dementia the priority for all involved in care.

In your role as primary caregiver, the first step towards resolving family conflict is taking time to reflect, reassess and remind yourself of what your role entails. You are someone who provides care to another person, but it is much broader than that. Perhaps you are the finance manager, or the housekeeper, or the scheduler, the cook, the decision maker, the grip on reality, or even the safety net. Perhaps you are all of these roles, plus a couple more.

When you take the time to reflect on these varied roles, you come to realize the summation of them is advocate. You are there for your person's best interest and safety.

Often, we think of advocating with medical providers, or wait staff; people outside of our inner circle, but you will also need to revive this role when navigating family conflicts. This is important to keep in mind, especially with family because it tends to be more difficult to maintain boundaries with those closest to you or your person. Reinforcing the nature of advocacy in your mind can help you 'hold the line' if you are receiving pressure to do something that you know is not in your person's best interest.

Situation: Family Members not on the Same Page – This is a common situation for most families given that many family members don't live in close proximity to the person with dementia. Even when in the same city, some family members have very limited in-person contact. When with the person with dementia for short visits, the person presents their "social best" so the family member leaves thinking everything is fine. When communication happens only by phone, the person with dementia also "sounds fine" and can carry on what appears to be a coherent conversation. While most family members will agree that their person is repeating the same stories or questions, they don't understand that this is a sign of a progressive dementia. Often a spouse or adult child who is the primary caregiver will try to explain to family members that the person's condition is getting worse. However, on the phone

or during a short visit, the family members often think the person sounds fine and the primary caregiver is making more of this than is necessary.

Many family members also have conflicting ideas about dementia. Some think that the person is simply getting older. For example, because the person's long term memory is largely intact in early stages, they minimize the short term memory issues that are causing problems in driving, decision making and managing financial and household affairs. They often attribute social isolation or disinterest in former activities as a "little depression" or "just getting older". In contrast, those closest to the affected person who seek medical advice often learn that the person has a dementia like Alzheimer's (the most common type of dementia). As they seek additional information through education programs and support groups, they come to understand the expected changes in dementia. But, when they try to explain this to other family members, they are sometimes put off. This will lead to unrealistic expectations about the person especially when decisions need to happen.

Even if the family all agree that a dementia is present, there is often not consistent sharing of caregiving responsibilities. Often the primary caregiver (usually a spouse or adult child) will report not getting help from other family members. Some primary caregivers simply won't ask for help or even accept it when offers are made. In time, this leads to family members no longer offering assistance even if they are willing to do so.

POSSIBLE SOLUTIONS:

It is essential for the family to get on the same page in order to support what is best for the person with dementia. Much of the initial solution(s) will reside with the primary caregiver who will be responsible for sharing important medical information with family members. We suggest the following:

- Arrange an in-person family meeting if possible, allowing out of area family members to listen in via phone. Ideally, scheduling a visit with the medical provider and/or with a social worker can be very productive as this objective professional can explain the diagnosis, current stage of illness and answer questions the family may have.
- Primary caregivers, who are the medical power of attorney, can also copy or share the physician progress notes with family members via mail/email.
- Provide routine updates to family members so they can understand changes that are occurring in memory, thinking, behavior and function.

- Invite family members to arrange extended visits where they are more likely to observe the changes that are being described by the primary caregiver.
- Outline what help is needed, in order to ask for and accept help and other forms of support from family members.
- Provide education materials that you find helpful to other family members such as links to archived Beacon newsletters, BAI Online education programs (www.banneralz.org/dementialogues) and the Alzheimer's Association (www.alz.org).

Situation: Blended Families: Not so long ago, blended families were the exception, rather than the rule. Currently, blended families resulting from multiple marriages or adoptions are more common.

Though the intention may have been the Brady Bunch, most blended families don't experience the ease of meshing that this popular TV show did. There are many factors that can contribute to the unique strain of the blended family including when the blend occurred. Even if challenges have been resolved, old wounds can resurface when dementia enters the family. If the marriage happened when the children were young, the family has had many more years to solidify bonds. In later unions, adult children ideally have a more mature attitude about the marriage, but may not bond with the new spouse in the same manner.

Another dynamic to consider is who will be identified as the primary caregiver to the person with dementia. If the natural parent has dementia, children can become territorial towards non-natural children and the spouse. Adopted children can feel resentment or jealousy towards the natural children for perceived favoritism. When the "new" spouse is the primary caregiver, natural children can become concerned that their parent's best interests aren't at heart, or even that inheritance is being spent unwisely on care – particularly residential care. An "us vs. them" mentality can begin to surface.

POSSIBLE SOLUTIONS:

- Agree that keeping your person's needs, comfort and predetermined wishes will remain at the center of all decision making.
- Communicate, communicate, communicate. Keeping everyone on the same page is key to restoring a sense of unity in a family that has become divided. Be open with all siblings about diagnosis, care and progression.

— continued on back panel

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.



Ask The Expert

Helle Brand, PA
Stead Family Memory Center

Dear Helle,

Our oldest granddaughter is getting married this summer in another state and our daughter is insistent on my husband attending. He was diagnosed with Alzheimer's about 5 years ago and is now quite confused. He is most comfortable at home, so I feel that taking him to the wedding will be way too confusing for him and much too stressful for me. However, my daughter thinks I am being too overprotective and keeping him from celebrating his granddaughter's wedding, even though most of the time he doesn't remember having any grandkids at all! I know that this is an important event and I don't want to disappoint, but how can I help her understand the demands this will put on both of us?

Sincerely,
Paula

Dear Paula,

This is certainly a common situation that we encounter with families. Whenever there is a milestone celebration such as a wedding, graduation, funeral or reunion, families think that everyone should be included – even the person with dementia. Most don't consider the person's condition or appreciate how the stress of these events impact that person. Even though most of these celebrations are uplifting, they cause undue stress on the person who is struggling to remember who people are, keep pace with conversations and endure lengthy gatherings. As you know, this is a recipe for disaster that could occur at the gathering or upon returning home if we don't factor these things in.

First, we must consider the stage of illness of the person with dementia. During the early stages of dementia, many can tolerate travel and celebrations. However, modifications will need to be put into place. By the moderate stage of dementia, travel is much more challenging with growing confusion and memory loss, making it more difficult for the person to remember family members and old friends, and to follow conversation.

Next, we must consider the well-being of the person with dementia. If we really care about this person, then we understand that now is a time when routine and predictability provide comfort. I think it is important to ask yourself "For whom is this most important?" Since travel to another state and lodging in an unfamiliar place (even if in your daughter's home) will add to confusion, this must be factored in as it relates to his well-being. If he becomes more confused and anxious, this undermines his well-being and may diminish his enjoyment and/or ability to tolerate being at the wedding; which may even impact other wedding guests.

If you decide to take him along, plan to arrive a few days early and keep the same routine as you did at home. I'd recommend you get a hotel room to allow for quiet and adequate rest. On the day of the wedding, plan to arrive right before the wedding. Following the wedding, go to a quiet place until the reception. Once that begins, come for the dinner and maybe one quick dance with the bride, but then it is time to end the celebration and get back to the room. Get a good night sleep and try to get a mid-day flight to return to the routine of home.

Remember if he doesn't attend, all is not lost. Your options then are to arrange for respite care for him at an assisted living facility, have a trusted friend stay with him; or arrange for a home care agency to come stay with him. You can attend the wedding and take ample photos and get a video to show him when you return. With today's technology, you might even be able to use phone applications (like Facetime) so he can see the bride and groom and say a quick hello! Perhaps the bride and groom or your daughter can make a visit at a later date and share stories with him as he will surely hear about the event even if he can't fully follow the conversation. Help your daughter know that this is an important event for you too and you want to be able to be present and enjoy this celebration without the added stress of your husband.

I hope these suggestions will be helpful so that you can enjoy this upcoming celebration.



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: bainfo@bannerhealth.com



Family Conflict: Weddings, Funerals and Dementia

— continued from inside

- Assign tasks to family members. If there are feelings of uneven distribution of care, or favoritism, providing opportunities to get involved can help ensure everyone feels they are an equal part of the family and may help them better understand the person's care needs.

Situation: Unresolvable Conflict – Sometimes, despite our best effort and intention, conflicts are unresolvable and a division amongst family members occurs. While certainly not ideal, understand this does occur in families under the strain of dementia. Conflict is usually about medical decisions as the disease progresses, movement into residential care, or financial decisions.

POSSIBLE SOLUTIONS:

- Clearly communicate conflicts and boundary issues with the affected party.
- Ensure you have the legal rights to make decisions that are contrary to other family members. A Power of Attorney for health, mental health and financial decisions are the minimum required. If conflict persists in decision making, you may need the counsel of an elder law attorney to seek guardianship or conservatorship.

- Communicate with professionals that have an interest in your person, to gather support, advice and recommendations. This could include medical providers, social workers, nurses, bank personnel, financial planners, attorneys and residential care staff.

In summary, family conflict is common and expected during the course of dementia. Keeping your person's best interest in the center of the conflict is of the utmost importance. Combined with open communication and working as a team, your family can succeed in making the best decisions possible.

To learn more about these and other family situations and solutions, join our Dementia Dialogue Webinar on Wednesday, February 15 at 12N Arizona time. Register at www.banneralz.org/dementialogues.



CAREGIVER EDUCATION PROGRAM SCHEDULE

February/March 2017

FEBRUARY

Dementia Friendly Tempe Presents: "Return Me Safe: Tempe Police Department Safety Programs"

Learn about Tempe Police Department's program to identify, locate, and return a lost person who cannot provide personal information. We will also share information about Smart 911, Lock Box, and Vial of Life safety programs.

Wed., February 8; 1:00 – 2:30 p.m.

Tempe Public Library

3500 S. Rural Road, Tempe

To register, call (602) 839-6850

Emotional Changes: Understanding Symptoms Beyond Memory Loss

It is well recognized that Alzheimer's disease causes memory loss. This program focuses on helping you better grasp the common emotional changes that may occur in the person with AD. Learning to better understand emotional changes can help you to increase your level of empathy and reduce caregiver frustration.

Wed., February 8; 10:30 a.m. – Noon

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

To register, call (623) 832-3248

AND

Thurs., February 16; 10:00 – 11:30 a.m.

BAI, 901 E. Willetta Street, Phoenix

To register, call (602) 839-6850

Dementia Dialogues Webinar Series: Family Conflict: Weddings, Funerals and Dementia

Life stages can bring out the best in families and the worst. This Dialogue explores practical ways to reach out for help within the family system and when it may be necessary to create your own chosen family. This webinar/teleconference series will parallel the monthly Beacon newsletter and expand upon important topics that are our readers have requested in the comfort of your own home/office.

Wed., February 15; Noon – 1:00 p.m.

(AZ Time). To register, visit www.banneralz.org/dementiadialogues or call 623-832-3248.

Communication: Avoiding Arguments

This class reviews changes in communication as dementia progresses and the common mistakes that caregivers make leading to arguments. A variety of alternative strategies are introduced and practiced during class so that caregivers can walk away with new techniques to immediately put into place.

Tues., February 21; 10:00 – 11:30 a.m.

Mesa Red Mountain Library

635 N. Power Road, Mesa

AND

Mon., February 27; 4:00 – 5:30 p.m.

BAI, 901 E. Willetta St., Phoenix

To register, call (602) 839-6850

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

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

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

To register, call (602) 839-6850

AND

Mon., March 27; 4:00 – 5:30 p.m.

BAI, 901 E. Willetta Street, Phoenix

To register, 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.

Please turn over for more classes →

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).**

Thurs., March 28; 1:00 – 2:30 p.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (623) 832-3248

MULTIPLE MONTH CLASSES

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.

Wed., February 1; 10:00 a.m. – Noon
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (623) 832-3248
AND

Tues., February 14; 10:00 a.m. – Noon
Tues., March 14; 4:00 – 6:00 p.m.
BAI, 901 E. Willetta St., Phoenix
To register, call (602) 839-6850

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.

Tues., February 7; 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

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.

Fri., February 17; 2:00 – 3:30 p.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (623) 832-3248
AND

Thurs., March 30; 10:00 – 11:30 a.m.
BAI, 901 E. Willetta St., Phoenix
To register, call (602) 839-6850

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).**

Wed., February 22; 9:00 – 10:30 a.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (623) 832-3248

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., February 23; 4:00 – 5:30 p.m.
Thurs., March 23; 10:00 – 11:30 a.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.
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.**

Tues., February 28; 9:30 – Noon
Wed., March 29; 1:00 – 3:30 p.m.
BAI, 901 E. Willetta St., Phoenix
To register, call (602) 230-CARE (2273)
AND

Wed., March 22; 10:00 a.m. – 12:30 p.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (602) 230-CARE (2273)



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