



Visiting Notes for Family and Friends

John and his wife Sheila looked forward to retirement when they moved to their new 55+ active adult community. During their first 3 years in the community John reported that the “net worth of their social portfolio was never greater” as they engaged in many activities and had frequent dates with other couples for lunch and dinner. However, as Sheila developed symptoms of Alzheimer’s disease, John reported that their social portfolio “crashed.” Their invitations to social functions and activities seemed to go away as people learned of her condition. Social isolation set in for both of them. John and Sheila were left feeling very alone. Even their children were visiting and calling less, at a time when both needed the love, support, and the companionship of family and friends.

John and Sheila’s situation is not unique. Alzheimer’s disease (AD) and related dementias carry unwanted stigma in our culture. When many hear the word “Alzheimer’s” or “dementia,” there is an assumption made that somehow the affected person is unable to benefit from the world around him/her. Many will stop looking at the PERSON they knew and only look at the losses – not the strengths that still exist within. Family members and friends report feeling awkward when communicating with the PERSON who may be repetitive or perhaps forget details from the past. They quickly shift

their attention and/or conversation to the primary family caregiver assuming the person cannot understand the conversation. In support groups, it is common to hear family caregivers share their frustration about the lack of support they feel from family and friends. Visiting notes, important tips and conversation guides can provide much needed help for family and friends to keep in mind that this individual is still a person and their ongoing visits and phone calls matter.

Disclosing a dementia diagnosis is a tough decision for many given the stigma that exists. However, most family and friends who are close to the person probably recognize some changes. Without using the “A” or “D” words, many find it helpful to let those closest to the affected person know what is happening and how they can help. Provide only the facts that you think are needed when sharing the condition and outline specifically what you need. Learning to ask for and accept help is an important skill to adopt early in the condition. While some friends and family may distance themselves, you will benefit from those who are by your side. Consider these real examples as conversation guides.

- Richard, diagnosed with AD, had a close group of friends who enjoyed hiking each weekend. When Richard could no longer drive, his wife Jen made a

decision to talk with his best friend Mark in the group. Jen explained that Richard had a “memory condition” and his doctor had recommended he give up driving. She told Mark that Richard looked forward to spending time with this group of guys each week. She then asked, “Will you pick him up every Saturday for the hike and when you no longer think it is safe for him to join you, will you let me know?” With that information Mark agreed to do so. This arrangement lasted for almost 3 years.

- Lucy was living with early AD and enjoyed her weekly bridge club with friends. Lucy recognized it was a bit harder for her to play bridge in the evening. She decided to tell her group of friends about her condition and then she made “the ask” of her friends – to play bridge earlier in the day and keep inviting her to join them even as her condition progressed. Lucy made it clear that what she wanted most was their companionship. Lucy’s friends honored this request and included her until she moved into a residential setting.

Visiting the person at home or in a residential setting is often a struggle for family and friends. Yet these visits provide a wonderful source of connection for the person living with dementia. As memory loss progresses, the person will be most comfortable with memories from the past. Thinking is slower and word-finding issues may be prominent, but that doesn’t mean the person will not benefit from the visit. Planning for the visit will ensure greater success for all. Tips to consider providing to family and friends:

- Ask the visitor(s) to come during the person’s best time of the day and let them know how long a visit should be.
- If the visitor has not seen the person in a while, remind them who you are (e.g. “Hi Aunt Cathy, it’s your niece Angie. It’s so good to see you!”).
- Avoid asking, “Do you remember” questions. Instead, engage the person in favorite stories or memories from the past. Listen to the (repeated story or questions) like it is the first time you heard it! Let the visitors know what your person likes to talk about.
- Do something the person will enjoy. Let visitors know what the person might appreciate; such as watching a favorite TV show, enjoying a treat, playing a simple card game, or taking a walk.

Visiting Notes: Sherri was discouraged that her mom’s good friends and family members were no longer visiting her as in the past. Rather than getting angry she decided



to write an email to all of them and ask for their help. In her email, Sherri updated them on her mom’s condition and then provided specific requests and instructions. She wrote, “If you can come by for a visit each week, mom would love to see you and hear about your life. Just a 15-30 minute visit mid-day will mean the world to her. She remembers her childhood years the best and loves to talk about her family growing up in Michigan. You will bring her such joy by bringing your smile and allowing her to tell her favorite stories to you. Mom always lights up for a piece of chocolate so feel free to bring some along. Mom lives in the moment now. While she may quickly forget that you made a visit, please know that the moments you share with her bring her pleasure!”

Phone calls are an essential form of communication for families living at a distance from the affected person and caregiver. As dementia progresses, the person will lose the ability to call family and friends directly and many interpret this as a sign of the person becoming disinterested in them. Nothing could be further from the truth. Family and friends must understand that the phone has become complex for the person and yet can be an important tool to stay connected. Some families are using computers and/or phones with cameras to talk live to their family members. Just like in-person visits, family and friends should be prepared to lead the call and conversation. Tips to consider providing to family and friends:

- Ask the caller to call/FaceTime during the person’s best time of the day and let them know how long the call should be.
- Have the caller remind the person who they are (e.g. “Hi Dad, it’s your youngest son Jeff. It’s so good to hear your voice!”).

In an effort to be efficient with our community’s generous donations and better preserve the environment, the 2018 Beacon will be moving to an electronic version. Please email us at bannerresearch@bannerhealth.com to sign up for our web version. If you require a printed newsletter, please contact us at 602.839.6850.

- Avoid asking, “Do you remember” questions. Let the caller know what your person likes to talk about. Remind the caller to give the person plenty of time to respond to any questions that are asked of them.
- Encourage the caller to tell the person pleasant stories about their life. The goal of the calls is to keep the mood light and happy.

Visiting notes: Don and Ruth have 4 adult children and 9 grandchildren who live across the US. Due to their busy lives, they are rarely able to visit the couple. Ruth has had dementia for many years, but despite her growing confusion she loves to talk about her children. A couple of Don’s kids have shared how difficult it is for them to see their mom as she is now; so their calls and visits have dropped off. Don’s support group encouraged him to engage their children in more frequent phone calls. Don shares at a recent group, “I decided I would call each of my kids and talk to them about their mom. I told them how much she loves them and continues to talk about them even though she is confused. I asked them each if they would call Ruth once a week and just talk with her for a couple of minutes. I told them just to talk her about what they were up to and then to tell her how much they love her and what a great mom she is to them. I let them know that when Ruth gets off the phone with them, she is happy for the rest of the day.” Don continued, “I guess this has really worked because 3 of them are calling her regularly. Ruth is so happy and so am I.”

Going to dinner in a group can also be taxing for the person with dementia who may struggle to stay focused with multiple conversations and background noise. Whether out to a restaurant or staying home for dinner with family members or friends, it is important for the primary family caregiver to be able to enjoy the dinner as well. Assigning a “buddy” to keep the person with dementia engaged will be essential. However, the buddy will need coaching to feel successful.

Visiting notes: Caroline is the caregiver for her husband with dementia. They are gathering at her daughter’s home for Thanksgiving dinner. Since Caroline rarely gets much time with other family members, she decides she will ask for her grandson Tony to be seated by his grandfather during dinner. Caroline tells him, “Tony, I’d really appreciate you sitting by your grandfather during dinner today, so I can catch up with some family members. Grandpa loves to hear about how things are going for you in college. Why don’t you tell him about the fraternity you joined? Grandpa still remembers his fraternity and college years and will love to tell you all about it. When the two of you finish dinner, why don’t you take him to watch the football game – he loves that!”

Visits during advanced dementia create many challenges for family and friends to visit and connect with the person. However, it is still possible to create meaningful connections during this final stage of the illness. **Tips to consider include:**

- Visit during the time when the person is likely to be awake and plan to keep the visit under 30 minutes.
- Let the person know who you are as names and faces might not make sense. Remember that the person always knows that they are in the presence of someone who loves them!
- Keep the visit sensory. This means to use touch, taste, vision, hearing and smells. Use a scented lotion and give a light hand massage. Show them images/ pictures of favorite places or things. Give them a favorite treat, like ice cream. Go outside and feel the sunshine. Read aloud favorite prayers, scriptures or stories. A warm embrace and hearing the words, “I love you” may provide a sense of connectedness.

A beautiful reminder that you love and honor the person is to use familiar visits and activities combined with new techniques to stay connected. While dementia may be a disease of the brain, the spirit of the person remains intact. Using important tips and visiting notes, it is possible for families and friends to stay connected and bring meaning to the end.



www.banneralz.org
602.839.6900

Sentiments and Situations Group

is a support group to help caregivers to share and problem-solve difficult situations and feelings related to caregiving and dementia. Please join us on Thursday, December 14, 2017 from 12:30 – 2:00pm at Banner Alzheimer’s Institute, 901 E. Willetta St., Phoenix, First Floor Education Center.

Dementia Dialogue Webinar: Visiting Notes for Families.

Join the discussion on Wednesday, December 20, 2017, 12N – 1pm (AZ time). Registration required: www.banneralz.org/dementiadialogues. If you need to register for audio only, call 623.832.3248.

Is the thought of estate and financial planning overwhelming?

In a nutshell, estate planning is really what you want done with what you own. The good news is that you can provide for the people and causes important to you, such as Banner Alzheimer’s Foundation, by taking simple steps now. Creating your plan for the future can be easy and even enjoyable. To learn more, please contact us at 602.747.GIVE (4483) or plannedgiving@bannerhealth.com.

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



Holiday Gift Guide for the Person with Dementia and Caregiver

Mild Disease

- Telephone with pictures of people on speed dial – www.alzstore.com
- Electric medication dispenser – www.alzstore.com
- Medic Alert/Safe Return ID band – www.alz.org
- Gift certificate for grocery delivery
- Monthly cleaning services
- GPS on cell phone (check with your cell provider)
- Lifeline – www.lifelinesys.com
- Electric sonic toothbrush
- Hand-held shower head
- A gift certificate of your time such as a monthly lunch date

Moderate Disease

- Food basket with non-perishable items
- Bathroom grab rails
- Favorite bath products and a nonskid safety surface for tub
- Cleaning help
- Respite services such as in-home companion or adult day programming
- Vintage videos and music – www.alzstore.com
- Subscription to "Reminisce" magazine – www.reminisce.com
- Family photo album labeled with who is in each picture and where it was taken

Advanced Dementia

- A Rollator-type walker with two wheels or rear wheel retractable brakes, seat, and basket (no hand brakes)
- Gift certificates for care supplies including disposable adult briefs
- Respite care
- Scented oils, especially lavender and citrus for massage
- Picture books that represent favorite interests, landscapes
- Music
- Coloring books and crayons

Caregiver Gifts

- The gift of time: coupons for cleaning the house, preparing a meal, mowing lawn, respite times that allow the caregiver time off to focus on what he/she needs.
- Gift Certificates: Restaurants and laundry/dry cleaning services, especially those that deliver; lawn care services; computer/technology support; maid services; personal pampering services such as massages, facials, manicures/pedicures.
- The gift of listening: Accompany the caregiver to a support group, weekly calls, routine "thinking of you" notes
- Subscription to a favorite magazine, Sirius XM radio, Netflix
- Things to do while alone such as iPad with games, e-reader, etc.



CAREGIVER EDUCATION PROGRAM SCHEDULE

December 2017/January 2018

December

Date	Time	Name of Class	Location	To Register
Dec. 5, Tues.	12:30pm – 2:00pm	Denial: Understanding Why Your Person Doesn't Understand	BAI	602.839.6850
Dec. 6, Wed.	10:00am – 11:30am	As Dementia Progresses	BSHRI	623.832.3248
Dec. 6, Wed.	1:00pm – 3:30pm	Banner Brain Health Program	BAI	602.230.CARE (2273)
Dec. 7, Thurs.	4:00pm – 5:30pm	After the Dementia Diagnosis (formerly COMPASS)	BAI	602.839.6850
Dec. 11, Mon.	10:00am – 11:30am	Medications for Dementia: What Are They and What Can I Expect?	BAI	602.839.6850
Dec. 12, Tues.	10:00am – Noon	Planning Ahead Class for Caregivers	BAI	602.839.6850
Dec. 13, Wed.	1:00pm – 2:30pm	Dementia Friendly Tempe Presents: Mindfulness Matters	Tempe Public Library	602.839.6850
Dec. 19, Tues.	10:00am – 11:30am	Help at Home: Support for the Person Living at Home	Mesa Red Mountain Library	602.839.6850
Dec. 20, Wed.	9:00am – 10:30am	Behaviors: Expressing What Words Cannot	BSHRI	623.832.3248
Dec. 20, Wed.	Noon – 1:00pm (AZ Time)	Dementia Dialogues Webinar: Visiting Notes for Families	Online	www.banneralz.org Under Events & Education

Banner Alzheimer's Institute (BAI Downtown Phoenix)
901 E. Willetta St., 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

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

Tempe Public Library
3500 S. Rural Rd., Tempe
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 24-48 hours after live session or call 623.832.3248



January

Date	Time	Name of Class	Location	To Register
Jan. 9, Tues.	10:00am – 11:30am	Everything You Always Wanted to Know About Dementia	BAI	602.839.6850
Jan. 10, Wed.	1:00pm – 2:30pm	Dementia Friendly Tempe Presents: Become a Dementia Friend!	Tempe Public Library	602.839.6850
Jan. 10, Wed.	2:00pm – 3:30pm	After the Dementia Diagnosis (formerly COMPASS)	BSHRI	623.832.3248
Jan. 17, Wed.	10:00am – 10:30am (AZ Time)	Dementia Dialogues Webinar: Advocating with Legislators	Online	www.banneralz.org Under Events & Education
Jan. 18, Thurs.	9:00am – Noon	Memory Loss-When to Take the Keys? Conference	Grace Bible Church	623.207.1703
Jan. 18, Thurs.	10:00am – 11:30am	After the Dementia Diagnosis (formerly COMPASS)	BAI	602.839.6850
Jan. 23, Tues.	12:30pm – 2:00pm	Activities: Filling the Day with Meaning and Purpose	BAI	602.839.6850
Jan. 25, Thurs.	10:00am – 11:30am	After the Dementia Diagnosis (formerly COMPASS)	Mesa Red Mountain Library	602.839.6850
Jan. 26, Fri.	1:00pm – 2:30pm	Emotional Changes: Understanding Symptoms Beyond Memory Loss	BSHRI	623.832.3248
Jan. 30, Tues.	9:30am – 11:00am	Emotional Changes: Understanding Symptoms Beyond Memory Loss	BAI	602.839.6850

Banner Alzheimer’s Institute (BAI Downtown Phoenix)
901 E. Willetta St., 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

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

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

Grace Bible Church
19280 N. 99th Ave., Sun City
Register at: 623.207.1703

Dementia Dialogues Webinar Series
Register at: www.banneralz.org/dementialogues
Please note that all webinars are recorded and archived on website 24-48 hours after live session or call 623.832.3248



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.