



## Managing the Negative Emotions from Caregiving

Alzheimer's disease (AD) is a disease of aging. Its main features include a gradual loss of memory and other cognitive abilities. Over time, the affected person becomes more simplistic in their thinking and behavior and more dependent on others for simple everyday activities. This places increasing stress on the caregiver on multiple levels. None of us are born *knowing* how to care for a person with AD. However, understanding the disease and how it affects the person can provide us insights into caring for them. Likewise this can help us better understand and manage our own emotions as we do so.

Up until the past century, few people survived to the at-risk age for developing AD thus, the prevalence of AD was not large enough to garner world-wide attention. Add to that the fact that prior to the discovery of microbes, there were many myths about the causes of disease. Most people thought dementia occurring in old age was simply aging and many attributed dementia to "hardening of the arteries". In 1906, Dr. Alois Alzheimer, a German physician and pathologist, described what he saw under the microscope when looking at the brain of a 54 year old woman whom he cared for prior to her death. She had the classical clinical features of memory loss progression.

In addition, he found abnormal deposits in the brain called plaques and tangles. Ultimately, the disease took his name – Alzheimer's disease. As medicine advanced and people began living to record old ages, there were increases in age-related diseases like AD. By the 1970s, it was becoming increasingly evident that the frequency of AD was growing and would continue to do so, creating a significant burden on families and society.

In AD there is the loss of connections between nerve cells (neurons) and weakening along with death of neurons. Initially, no symptoms are evident, but gradually, as more neurons are affected, subtle changes start to occur. These may be difficult for the affected person or their family to recognize. However, as the disease progresses symptoms start to become more obvious. The person may become more withdrawn, less social, talk less and become less responsive with family and friends. In these earliest stages, the symptoms may be mistaken for lack of affection. For example, a wife stated, "He no longer does what I ask him to do. I asked him to put the dishes away. He said he would. When I came back, he had not done so and was on the couch watching TV!" This left the wife feeling dismissed or unloved as this is something her husband would have done in the past.

The early symptoms may also be mistaken for depression or if accompanied by sadness, may actually signify newly developed depression. In such a case the family member may develop feelings of guilt because they have not “done enough” to please them. For example, a son may say, “It is my fault that I didn’t take more time to be with dad after mom died. I know this was a big loss for him and he didn’t have many friends or interests without mom.”

Over time (even years) symptoms start to become more obvious and form a pattern. Many families attribute the symptoms to aging until some incident occurs that requires attention, such as a car accident, getting lost on a familiar route, an embarrassing incident or financial problems arise. It is not uncommon for either the person or family to delay seeking a diagnosis. In fact, most patients and families fear the loss of decision-making, autonomy and stigma associated with the disease. Many families want to spare the person from knowing that they have AD. While this may be true in some instances, gently engaging the person in conversation often will result in some admission of memory loss by that individual.

When a dementia diagnosis is made, the caregiver, typically a spouse or adult child, will experience a multitude of emotions. They must come to grips with the changes in their loved one both now and in the future. And, they know that there will be a shifting of roles and responsibilities. This can trigger a variety of emotions ranging from sadness to anger; overwhelm to frustration. In fact, caregivers are coping with grief and loss.

Caregivers may experience different levels of the five stages of grief: denial, anger, bargaining, depression and acceptance. These were described by Kübler Ross relating to the death of loved ones. However, AD signifies a slow death in many ways and going through similar stages has been described by many caregivers.

**Denial** is common, particularly early in the illness as families try to convince themselves that the person hasn’t really changed that much. Examples include, “She doesn’t forget much. No more than the rest of us.” “He’s okay to drive around the area – he’s got his phone if he gets turned around.” “Mom is not that bad. She can live alone.”

**Anger** can take on different facets. Anger can be directed at the person, blaming them for their failings. It can be directed at oneself with self-blame for what is occurring. It may be directed at fate for dealing such a mean blow. It is a natural reaction to a very painful realization. A

common example includes, “All our lives we sacrificed for others, for the family. We saved a bit for our golden years. We wanted to travel and now we can’t go anywhere.”

**Bargaining** is when we try to reach some sort of compromise. This stage often signifies a recognition of what is happening and an attempt at trying to deal with it in some logical, reasonable manner. Examples include, “This is no longer the person I married. If only she would do this, we’ll be ok.” “If I can just get Dad to understand that he needs help in the home, then he can stay where he is longer.” Alas, there is no arguing with neuronal degeneration. Harsh reality hits.

**Depression** can result for many family caregivers as losses mount, self-care is neglected and isolation limits the ability to nurture self. Ultimately, the practicality of having to deal with the situation and do what one can do, acceptance and pragmatism may prevail or co-exist with depression. Help for many can be found through the counsel of a support group or confidant. Others may need to seek professional help.

**Acceptance** comes for many family caregivers as they come to understand that their person is doing their best and that help is needed to go the distance. Most have found others to support their efforts and they continue to stay open to new possibilities to learn and grow. Many share their lessons learned with others as a way to give back. Examples include, “I have learned so much about Alzheimer’s, I enjoy meeting with others as they are becoming caregivers.” “She couldn’t come into my world, so I joined her journey. When I did, her world became better and so did mine!”

**Empowerment** is a sixth stage that can be added to Kübler-Ross’s stages of grief. Since the person with AD is still alive as the caregiver passes through the stages of grief, there is continued opportunity to grow and respond. This can be done through:

- **Education:** The more the caregiver learns about AD and its features, the better they can manage the numerous demands with better planning for their person and self. Understanding the progression of AD allows caregivers the opportunity to recognize what is happening and better adapt and adjust. Attending support groups can be very helpful for education and for developing a social support system as the caregiver learns to navigate the disease and the various

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## Ask The Expert

Edward Zamrini, MD  
Cleo Roberts Memory Center Director  
Banner Sun Health Research Institute

Dear Dr. Zamrini:

*My husband has had Alzheimer's disease for the past 7 years. One year ago I had to move him to a memory care unit near my home as I began having bad health issues. My friends (who never visit him) ask me routinely, "How is he doing?" What am I supposed to tell them because I don't think they really want to know? This makes me angry at them. Don't they get that he is getting worse? In fact, I feel angry most of the time. Even though he is in memory care, I am there every day to visit him. I have no life of my own and don't see an end to this situation. But then I feel guilty as I don't want to wish my husband dead. How can I cope with these emotions?*

*Signed,  
Betty*

Dear Betty,

I am sorry for the losses that you continue to experience as your husband's Alzheimer's disease progresses. Often well-meaning friends and families don't know what to say. In their attempt to be helpful, their thoughts, words or (lack of) actions may be hurtful. Most caregivers report feeling angry, abandoned and guilty all at the same time. These are very common emotions!

I am glad you are in touch with your feelings. Now is the time to act on them. One of the most important steps is finding continued support as you go through this process. If the memory care unit provides a support group, I'd encourage you to join as I would imagine that other caregivers are experiencing the same range of emotions. Finding support from others is often the best therapy of all! You may consider asking your friends to join you for a visit sometime but provide them with ideas on how they can successfully interact with your husband. Remember, they have not walked in your shoes and don't understand Alzheimer's like you do – teach them.

So finally, if you have feelings of prolonged sadness, it is important that you talk with your primary care provider as you may be suffering from depression that may benefit from medication and/or professional counseling.

No doubt, you are a kind and loving wife which your husband can still feel – even if he can't call you by name. Your love matters and caring for yourself is more important now than ever. I wish you all the best.

Did you know that you can honor physicians and staff at Banner Alzheimer's Institute through a gift of support? For more information, please contact us at 602.747.GIVE (4483) or visit [www.banneralz.org/support-our-mission](http://www.banneralz.org/support-our-mission).



[www.banneralz.org](http://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. In April, we will discuss "Emotional Impact of Caregiving." Join us on Thurs, April 13, 2017 from 12:30 – 2:00pm at Banner Alzheimer's Institute, 901 E. Willetta Street, Phoenix, First Floor Education Center.

### **Dementia Dialogue Webinar Managing the Negative Emotions from Caregiving**

Dr. Edward Zamrini  
Wed., April 19, 2017  
12N-1pm (AZ time)  
Registration required:  
[www.banneralz.org/dementialogues](http://www.banneralz.org/dementialogues)  
Call 623.832.3248

## Have a Question?

To submit your question for future consideration email us at: [baiinfo@bannerhealth.com](mailto:baiinfo@bannerhealth.com)



## Managing the Negative Emotions from Caregiving (con't)

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emotions they may experience. (\*\*Note that BAI has numerous in person and online education classes, [www.banneralz.org](http://www.banneralz.org))

- **Research:** Research may be the key to eliminating, or at least significantly delaying AD. Scientists have learned a tremendous amount over the past several decades. The approach to patients has significantly improved despite the absence of new approved drugs against the disease. While there is much more to learn, through research we have a clearer path ahead of us on what steps need to be taken to beat this disease. To learn more, we invite you to join the Alzheimer's Prevention Registry, [www.endalznow.org](http://www.endalznow.org).
- **Empathy and Love:** Regardless of the stage of the disease and of scientific advances, we should never lose sight of our humanity and what makes us greater than our flesh and bones. People with AD can still sense love and kindness towards them. The most successful families are those who understand this at a deep level. A focus on the person's quality of life and well-being can assist families to minimize their own distress and find joy and laughter in the day to day.

- **Altruism:** Many people with AD who participate in clinical trials express, "I understand I may not benefit, but if this may help somebody else, I want to do it." Caregivers often express the same feelings about being a partner in a study or in their efforts to participate in a Walk to End Alzheimer's disease or become Alzheimer's advocates with local and national policy leaders.

In summary, it is common and expected for caregivers to experience a wide range of emotions as the lives they have known are now significantly changed due to AD. Recognizing feelings of grief and loss are helpful along with a variety of strategies to support caregiver health and well-being. To learn more about managing the emotions of caregiving, join our Dementia Dialogue on April 19. Register at [www.banneralz.org/dementiadialogues](http://www.banneralz.org/dementiadialogues).





# CAREGIVER EDUCATION PROGRAM SCHEDULE

April/May 2017

## April

Date	Time	Name of Class	Location	To Register
April 1, Sat.	10:00 a.m. – 1 p.m.	<b>2nd Dementia Friendly Tempe Community Summit: New Strategies in the Fight against Alzheimer's disease</b>	Southwest College of Naturopathic Medicine	602.839.6850
April 4, Tues.	10:00 a.m. – Noon	<b>As Dementia Progresses: Next Steps for Caregivers</b>	BAI	602.839.6850
April 5, Wed.	10:00 – 11:30 a.m.	<b>Directions for Caregivers After the Dementia Diagnosis</b>	BSHRI	623.832.3248
April 10, Mon.	4:00 – 5:30 p.m.	<b>Directions for Caregivers After the Dementia Diagnosis</b>	BAI	602.839.6850
April 11, Tues.	10:00 a.m. – Noon	<b>Planning Ahead Class for Caregivers</b>	BAI	602.839.6850
April 11, Tues.	1:00 – 2:30 p.m.	<b>Travel: Planning for Success</b>	BSHRI	623.832.3248
April 12, Wed.	1:00 – 2:30 p.m.	<b>Dementia Friendly Tempe Presents: My Favorite Apps</b>	Tempe Public Library	602.839.6850
April 12, Wed.	1:00 – 3:30 p.m.	<b>Banner Brain Health Program</b>	BAI	602.230.CARE (2273)
April 17, Mon.	4:00 – 5:30 p.m.	<b>Residential Care: When Moving Becomes the Best Option</b>	BAI	602.839.6850
April 18, Tues.	10:00 – 11:30 a.m.	<b>Behaviors: Expressing What Words Cannot</b>	Mesa Red Mountain Library	602.839.6850
April 19, Wed.	10:00 – 11:30 a.m.	<b>Activities: Filling the Day with Meaning and Purpose</b>	BSHRI	623.832.3248
April 19, Wed.	Noon – 1:00 p.m. (AZ Time)	<b>Dementia Dialogue Webinar Series: Managing the Negative Emotions from Caregiving</b>	Online	www.banneralz.org under events/education
April 21, Fri.	10:00 a.m. – 12:30 p.m.	<b>Learning to Provide Hands on Care: A skills lab for family caregivers</b>	Foundation for Senior Living Caregiver House	602.839.6850
April 26, Wed.	10:30 – 11:30 a.m. (ALTCS)	<b>Financial Assistance: Understanding ALTCS &amp; VA Benefits</b>	Pyle Adult Recreation Center	602.839.6850
April 26, Wed.	11:30 a.m. – 12:30 p.m. (VA Benefits)	<b>Financial Assistance: Understanding ALTCS &amp; VA Benefits</b>	Pyle Adult Recreation Center	602.839.6850

**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

**Southwest College of Naturopathic Medicine**  
2140 E Broadway Rd, Tempe  
Register at: 602.839.6850

**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

**Foundation for Senior Living Caregiver House**  
1201 E. Thomas Road, Phoenix  
Register at: 602.839.6850

**Pyle Adult Recreation Center**  
655 E. Southern Ave., Tempe  
Register at: 602.839.6850

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



# May

Date	Time	Name of Class	Location	To Register
May 3, Wed.	10:00 a.m. – Noon	<b>Planning Ahead Class for Caregivers</b>	BSHRI	623.832.3248
May 9, Tues.	4:00 – 6:00 p.m.	<b>Planning Ahead Class for Caregivers</b>	BAI	602.839.6850
May 9, Tues.	1:00 – 3:30 p.m.	<b>Banner Brain Health Program</b>	BSHRI	602.230.CARE (2273)
May 10, Tues.	10:00 – 11:30 a.m.	<b>Communication: Avoiding Arguments</b>	BSHRI	623.832.3248
May 10, Wed.	1:00 – 2:30 p.m.	<b>Dementia Friendly Presents: Legal and Financial Planning for Alzheimer’s disease</b>	Tempe Public Library	602.839.6850
May 11, Thurs.	9:30 – 11:00 a.m.	<b>Communication: Avoiding Arguments</b>	BAI	602.839.6850
May 16, Tues.	10:00 a.m. – Noon	<b>Planning Ahead Class for Caregivers</b>	Mesa Red Mountain Library	602.839.6850
May 17, Wed.	Noon – 1:00 p.m. (AZ Time)	<b>Dementia Dialogue Webinar Series: I Have Never had a Ticket in my Life: How to handle driving</b>	Online	www.banneralz.org under events/education
May 18, Thurs.	10:00 – 11:30 a.m.	<b>Denial: Understanding Why Your Person Doesn’t Understand</b>	BAI	602.839.6850
May 18, Thurs.	1:00 – 2:30 p.m.	<b>Finding Meaning While Living with Loss</b>	BAI	602.839.6850
May 22, Mon.	1:00 – 3:30 p.m.	<b>Banner Brain Health Program</b>	BAI	602.230.CARE (2273)
May 24, Wed.	10:00 – 11:30 a.m.	<b>Help at Home: Support for the Person Living at Home</b>	BSHRI	623.832.3248
May 25, Thurs.	10:00 – 11:30 a.m.	<b>Directions for Caregivers after the Dementia Diagnosis</b>	BAI	602.839.6850

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901 E. Willetta Street, Phoenix  
Register at: 602.839.6850

**Banner Sun Health Research Institute (BSHRI Sun City)**

10515 W. Santa Fe, Sun City  
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**To learn about upcoming education and support programs dates at:**

- Banner Alzheimer’s Institute, visit [www.banneralz.org](http://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](http://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