



Understanding Emotional Changes in People Living with Memory Loss

It is well recognized that Alzheimer's disease (AD) causes memory loss and through the progression of the disease behavioral changes are also common. There is often less discussion about the emotional changes that occur within the person. By narrowing our focus to the specific emotions the person with dementia may experience, we can offer a stronger level of empathy and reduce caregiver frustration. This article will review some of the common emotional changes in people living with AD and how they may shift through the progression of the disease. We will also discuss emotional changes that affect other types of dementia. Finally, we will explore how caregivers can use this information in order to be more present and supportive to their person with dementia.

Emotions fluctuate with changes in the brain and are responsible for directing our attention and motivating our behavior. We identify what is happening in the environment around us and emotions assist us in responding to events and situations. Neurodegenerative disorders like dementia, trigger patterns of emotional and behavioral changes based on the area(s) of the brain affected. Depending upon the phase of the disease, a variety of emotional changes follow. Emotion and memory are closely connected. Research supports the notion that emotion regulation requires cognitive control. Therefore, as memory fades our ability to have control over our emotions becomes more limited.

What are the most common emotional changes that we see as someone develops symptoms of dementia?

Often feelings of *apathy* or indifference surface. For example, the person used to enjoy being around family for a celebration. Now the care partner announces that they

have a birthday party to attend and observes that the person appears not to be interested or even refuses to attend. If the person does attend, he seems quieter than in the past and/or uninterested in the festivities altogether.

Apathy can deflate a person's *motivation to initiate and complete tasks*. Quite often, a spouse of someone with dementia will complain, "He sits around on the couch most of the day when he used to be incredibly active". Or an adult child claims about her mother, "She used to be so helpful around the house with laundry and meals and now she doesn't even seem to notice them or offer help". Frequently there is a decline in participation in chores and routine tasks that once were simple. But now these tasks have become complex and overwhelming.

Accompanying *apathy*, we often see a *loss of interest in socializing and a decline in emotional connections*. The person can have trouble participating in conversations due to the challenges dementia places on verbal communication. Family and friends may describe the person becoming more self-involved and less responsive to those around her. In some cases, care partners feel incredibly hurt as they interpret these emotional changes to mean that their person doesn't care about them. Instead, it is important to remember this is part of the disease.

Likewise, we may see *loss of interest* in previously enjoyed hobbies. Recently, a gentleman with early dementia expressed to his daughter that, "all the people at the recreation center do is grumble" and he would not return to play bridge any longer. In this example, it may be that *apathy* or lack of initiative interfere with his ability to remain engaged

in a game he has enjoyed for years. It is also possible that the complexity of the game may be too challenging for him to take pleasure in any longer.

Apathy may trigger a belief from family members that their person is giving into the disease. This creates challenges within those relationships. In reality, the disease affects the person's ability to actively change their behavior. In truth, apathy may be most apparent and more distressing to the family than to the person. It may act as protection, as it functions in place of sadness, worry or distress. Apathy may be difficult to treat with medication, but structure, support and encouragement may be even more valuable.

With dementia, *depression* is common. The person may be more aware of their limitations and feel sadness, tearfulness or feelings of failure or despair about the future. While some people seem unaware of the effects of their dementia on other people, many experience feelings of guilt about how their disease impacts family and friends. Others may appear more irritable, cranky and seem to have a shorter fuse as they have trouble sorting out their emotions.

Research has linked a direct connection to depression and dementia. As many as half of people with late life depression also have a cognitive impairment. In addition, depression has been both identified as a risk factor and an early symptom of dementia. Depression can limit quality of life for people with AD and other dementias and may make cognitive limitations appear worse. Depression can limit a person's performance on activities of daily living. It can also aggravate appetite and sleep problems already complicated by dementia. Use of medications can often have a positive effect on these symptoms.

Typically people with greater insight into their disease have greater depression. The change in mood is partly a reaction to having a progressive disease. Sadness may arise as the person remembers a close relative who declined from dementia or feels anxious or worried about passing on dementia to her children. Furthermore, the person may be greatly concerned about the impact or burden of the illness on the family adding to feelings of lack of control over the situation. In some cases, a person in this state may voice that if things were to worsen, she would not want to continue on. It is critical for family members to remind the person that they are valued and supported and seek consultation from the medical provider.

Depression is closely tied to a decline abilities and reduced independence as the person becomes more reliant on others for assistance and care. Feelings may be revealed in irritability, frustration or sadness. Moreover, undiagnosed or under-treated pain is linked with depression and something for caregivers to keep in mind.

Feeling nervous or worried is common in dementia and may be closely connected to depression. *Anxiety* can cause the

person to experience tension, racing thoughts or difficulty resting, relaxing or sleeping. The person may begin to avoid situations that cause worry. Often symptoms of anxiety are connected to decline in memory and feeling lost as a result. For example, a woman with dementia may have *anticipatory anxiety* as she worries about forgetting an important upcoming event or appointment.

With memory loss, the person may fear the progression of the disease and increased dependency on others around them. As the person becomes more reliant on their caregiver, fear or panic increases when they are not together. This can trigger a *separation anxiety*. The person may search or call out for the caregiver or shadow them, trying to stay as close to their caregiver as possible when they are near. Remaining close to their caregiver is important as the caregiver has become their memory, comfort and guide. This can be frustrating to the caregiver. It is key to act gently, offering a hug or kind verbal reassurance before redirecting the person.

Occasionally, *obsessive behavior, hoarding or collecting belongings* occurs and may be connected to loss of memory and loss of ability to organize. At times, it is associated to previous long term traumatic events if the person endured war, famine or economic downturn. It is important not to scold the person, but to let them keep things that offer comfort while subtly removing excessive or unsafe items out of sight.

Early in AD the person can appear more *dependent, fearful, indecisive and passive*. As discussed, the person in early stage often withdraws from family and friends and becomes less engaged even when encouraged to continue normal activities. More struggle surfaces in performing regular activities as memory fades. In addition, others may have criticized their performance, prompting the person to be less verbal and further withdrawing. Memory loss makes conversation more difficult to produce or follow. It helps to shorten or simplify the activity and reduce the amount of people involved to allow the person more opportunity to connect.

In moderate stage AD, the person withdraws further internally as the external world becomes too complex to manage. Therefore, the person often becomes more remote from friends and family. The disease progression creates a greater struggle with verbal connection. While the core person remains, families can report glimmers of emotional connectedness at times. One spouse reported her husband in moderate stage had been limited in his verbalizations. One morning she awoke to find him gazing at her and asked her, "Do you miss me?"

In more advanced AD, the person may more broadly retreat both physically and emotionally. The person displays limited facial expressions and responses. Family members report added difficulty staying emotionally connected to the person. While verbal connections wane, remember that sensory bonds through the use of touch and music can be strengthened.

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.

What are common emotional changes in other forms of dementia?

In those with Lewy Body dementia (LBD), the person often may experience rapid changes in their thinking which can create sudden mood changes. It can be difficult for family members to keep up with changes and some report it feels like a rollercoaster. Remembering to focus on seizing those clearer moments to enjoy activities and time together can be helpful.

People with Vascular dementia may suffer from Pseudobulbar affect (PBA) that causes involuntary or uncontrollable crying or laughing without a clear stimulus. Vascular dementia may also be linked with an increased occurrence of depression. Providing structured, predictable routines with soothing activities along with a medical consultation are useful.

In Frontotemporal dementia (FTD), common emotional symptoms of apathy, disinhibition and even feelings of elation or euphoria may be present. Some people experience mood irritability, sleep disturbances, depression as well as anxiety. Seeking additional support from expert medical providers and support staff is critical in best managing these symptoms.

— continued on back panel



Ask The Expert

Lori Nisson, MSW, LCSW
Director of Family & Community Services

Dear Lori,

I moved in with my sister after her husband died and she was lonely. The arrangement worked out well for both of us as we shared responsibilities, expenses and had fun together. Recently, I came to recognize she was developing dementia and I would have to help her more. She is in good physical condition and used to walk three miles a day. Now, she says she doesn't want to walk at all and I am frustrated that I have to do things she is still able to do but won't; like laundry, dishes and dusting. We get into arguments because she says I nag her. I am just trying to make sure she doesn't lose it completely. What should I do?

Sincerely,
Joan

Dear Joan,

Thank you for sharing your genuine concerns. Your sister's situation is shared by many people with dementia. The symptoms of apathy, social withdrawal and lack of motivation occur often in early to moderate dementia, like Alzheimer's disease. As her sister and care partner, these changes can be incredibly frustrating for you as you take on more of those responsibilities. In addition, it may be hard to accept that your sister is not trying to be difficult and may have lost some of the skills that once came easily to her. It makes sense to want to try to convince her to continue her walking as a means of preserving those abilities. But, due to dementia her capacity to reason, take initiative, and modify her behavior are compromised. Instead, you may have better success by telling her you need to get out for a walk and need her to join you to keep you company. You might ask her to "help you out" by folding a load of towels you have just washed and dried. Partnering allows you to assist with the tasks that may present a challenge for her and keep her engaged in things she still can do, while enhancing quality of life for both of you.

In addition, you might look into recreation center, adult day center or life enrichment programs developed specifically for people with dementia in your community to help offer structure and socialization. If you suspect she may be depressed, consult her medical provider. It is normal to grieve your sister's losses and the changes in your relationship, so don't forget to seek your own emotional support from friends, family or a caregiver support group to help sustain you through the progression of the disease.



www.banneralz.org
602.839.6900

Did you know 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

Have a Question?

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





Banner Health®

Banner Alzheimer's Institute
Banner Sun Health Research Institute

Banner Health
901 East Willetta Street
Phoenix, AZ 85006

Understanding Emotional Changes in People Living with Memory Loss

— *continued from inside*

Being more aware of these emotional changes in your person can help you to seek assistance from your person's medical provider for possible medications that may assist to effectively manage cognitive, depression, anxiety, sleep, mood instability or pain symptoms.

People in early stage dementia with emotional changes often respond well to early stage support groups where they can feel supported by peers who may experience similar feelings. In some groups, the care partner and person with dementia attend in separate spaces to allow for candidness in sharing feelings without risk of offending the partner.

Maintaining structure and creating opportunities for comfortable activities at a recreation or adult day center aligned with the person's current abilities can enhance quality of life. Keep in mind, the primary goal of activities is to help the person feel successful in what he can do, while creating a sense of purpose that can boost self-esteem and positive emotions. Reminiscing about positive long-term memories and engaging in safe, physical activities are beneficial in regulating mood and anxiety. As the disease progresses, consider activities that utilize the senses or involve interacting with children or animals. This will help your person feel upbeat and valued.

Recognize dementia and emotional changes interfere with the person's ability to initiate their own activities. Don't preannounce an activity too soon in advance. Rather, on the day of the activity, mention that you would like to attend an event (take a walk, run an errand) and that you would really like for that person to join you. By avoiding a "yes/no" question, you are less likely to receive the negative response. Using gentle persuasion, a direct approach and kind encouragement, you will more often experience success.

As someone who cares about a person with dementia, you can positively affect her quality of life by having a better understanding of the emotional impact of dementia and taking a compassionate and encouraging stance. It is important to remember that your person will often mirror your emotion. If you are calm and cheerful, he is more likely to reflect that back. This allows you to provide adequate support and increase your own feelings of acceptance in managing the complexities of the disease day to day. To learn more about this topic, attend the Dementia Dialogue Webinar/Teleconference on January 18, 2017, 12N-1pm AZ time. Register online at www.banneralz.org. Click on 'Events and Education' then 'Online Education' or call 623-832-3248.



CAREGIVER EDUCATION PROGRAM SCHEDULE

January/February 2017

JANUARY

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.

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

Mon., January 9; 12:30 – 2:00 p.m.

BAI, 901 E. Willetta St., Phoenix

To register, call (602) 839-6850

AND

Tues., January 10; 1:00 – 2:30 p.m.

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

To register, call (623) 832-3248

AND

Tues., January 17; 10:00 – 11:30 a.m.

Mesa Red Mountain Library

635 N. Power Road, Mesa

To register, call (602) 839-6850

Dementia Dialogue Webinar: Understanding Emotional Changes in People Living with Memory Loss

People with dementia often experience their own feelings of loss or even apathy. This Dialogue will explore how to better understand the person's emotional needs, provide adequate support and increase our own feelings of acceptance.

Wed., January 18; 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

Dementia Friendly Presents: "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.

Wed., January 11; 1:00 – 2:30 p.m.

Tempe Public Library

3500 S. Rural Road, Tempe

To register, call (623) 839-6850

FEBRUARY

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

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 (623) 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.

Please turn over for more classes →

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

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.

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

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.

Tues., January 10; 4:00 – 6:00 p.m.

Tues., February 14; 10:00 a.m. – Noon
BAI, 901 E. Willetta St., Phoenix

To register, call (602) 839-6850

AND

Wed., February 1; 10:00 a.m. – Noon

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., January 11; 1:30 – 4:00 p.m.

BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (602) 230-CARE (2273)

AND

Tues., January 31; 9:30 – Noon

Tues., February 28; 9:30 – Noon

BAI, 901 E. Willetta St., Phoenix

To register, call (602) 230-CARE (2273)

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).

Thurs., January 26; 10:00 a.m. – Noon

BAI, 901 E. Willetta St., Phoenix

To register, call (602) 839-6850

AND

Wed., February 22; 9:00 – 11:00 a.m.

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

To register, 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.

Mon., January 30; 2:00 – 3:30 p.m.

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

AND

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

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

