



Helping the Person with Dementia Feel Worthwhile

Throughout life, each of us as individuals derive our value or worth from the various roles we hold. Whether the role is as spouse, sibling, friend, volunteer, worker, etc., each provides meaning and purpose. In fact, it is fulfilling these roles that gives each of us a sense of worth. Many of the tasks done throughout the day revolve around that role fulfillment. It is the doing that gives worth.

The need to feel worthwhile does not change throughout life – whether through normal aging or when living with dementia. Each person desires the ability to actively engage in and fulfill the roles that are held dear. However, for many people living with dementia and their family members, there are great concerns that they will lose the skills, roles, achievements and personality that have defined them throughout life. That their sense of purpose and self-worth will be diminished. Added depression that can accompany dementia can add to feelings of diminished self-worth.

Family members and friends often struggle to find ways to help the person find a sense of worth as abilities change. If the focus is only on the losses versus the remaining strengths within the affected person, it will be more challenging to create meaning within each day which in turn, takes away a sense of self. One person living with dementia wrote that our attitudes about a person with dementia can lead to “learned helplessness.” That is, if we have little expectation of people living with dementia, we are quick to take away responsibilities and activities which can create helplessness.

However, filling your person's day with meaning and activities often becomes a challenge for caregivers. We are often unfamiliar with the tasks that these individuals carried out on their own for years to fulfill their roles. Additionally as the person's needs are changing, so in turn, caregivers must continue to adapt. While there is not a specific rule of thumb for enhancing self-worth in people living with dementia, there are some thoughtful strategies that can be helpful.

Where to begin:

Consider first, the role(s) your person has held important throughout life. Think about the tasks that were part of that role and how they completed them. This is not going to hold true 100% of the time, but old habits are a good place to start. For example, one woman held dear her role as a model and took pride in her appearance. Now living in a residential care community, each day she looked for affirmation from the staff before leaving her room. It was important for the staff to ensure that she indeed looked her best before going to breakfast. This was not vanity, but a sense of pride in looking her best for the day that included the care she took in doing what she could for herself. Keep consistent habits and routines in place as this will add to the person's strengths.

Next, think through what has changed. For most people with dementia, early in the disease, short-term memory will be compromised and will change their ability to participate as independently in activities. They will benefit from verbal prompts and cueing. Resist the urge to take over tasks as this will contribute to "learned helplessness" before the skills are completely lost. As there are changes with ability to stay focused on a task, remember to minimize background noises or distractions. When word finding issues appear, ask how you can help. In general, slow down and give the person time to respond. Watch for confusion if they don't understand what you are saying. Use short and simple commands providing choices whenever possible.

Modifying:

Once you take into account who your person was, and who they are now, you must reconcile the difference by modifying activities. Every activity can be adapted to meet current abilities and provide opportunities for participation. There are three main ways to modify throughout the course of dementia: time, participation and utilizing the senses.

- **Time:** Fatigue is the person with dementia's worst enemy. As a caregiver, you are constantly monitoring for signs of fatigue such as anxiety, agitation or other behavioral expressions. One way to anticipate and/or try to eliminate fatigue is to modify the time of activities. This can be done in two ways.
 - First, shorten the length of the activity. In general, a person in the early stage may be able to participate in an activity for 2-3 hours. Those in the moderate stage may engage for ½-1 hour while someone in the late stages will participate best for 15-30 minutes. This will vary based on the type of activity.

Keep in mind, the more your person has to engage-physically, mentally, or emotionally, the more fatiguing it will be, and consequently the shorter the activity will have to be.

- The second way to modify time is by listening to your person's 'rhythm.' Pay attention to the peaks and valleys in their energy levels and work with them when scheduling tasks. Notice your person's best time of day. Once armed with this knowledge, schedule the taxing, or fatiguing activities when your person is at their peak. When they are in a valley- do NOT schedule tasks that require a lot of energy.
- **Participation:** Activities can be modified by the level and type of participation for both you and your person. Early in the disease, your person may still be quite independent. Your role may be to offer reminders that it is time for certain tasks or activities to happen. Due to changes in planning and organization, you may need to gather all materials, or perhaps offer other cues to ensure they can complete the task. As the dementia progresses, you will need to take more of an active role in the execution of activities by offering limited, appropriate choices, or breaking the activity into more manageable steps. In the late stage, activities that are overlearned and familiar will work best.

Throughout the progression of the condition, it is important to include the person using intact abilities. A sense of self can be experienced through both active and passive participation. Rely on your personal knowledge of them to help guide which activities they will do and which they can act as a coach, or an active observer. Be sure to share what you know about your person with others so they too can stay engaged with the person.

- **Utilizing the senses:** Sensory information can be a help or a hindrance for a person with dementia. Through the entire course, be aware that sensory stimulation can cause overwhelm. Keep in mind that all information coming in through their senses requires more thought to understand than it did previously. The more thought, the more fatiguing it will be. Additionally, when the person is in the moderate stage, sensory input can start to become misinterpreted. Learn how much stimulation your person can tolerate so that the activity can be enjoyed. Too much noise, too large of a group, too much demand to complete a complex task are all examples of too much stimulation. If an activity requires a lot of attention or focus, try to remove any unnecessary sensory information.

Did you know you could help us make the breakthrough that will change lives for generations to come?

To support the work of Banner Alzheimer's Foundation, call 602-747-GIVE (4483) or visit www.banneralz.org/support-our-mission.



Ask The Expert

Heather Mulder
Outreach Program Manager

Dear Heather,

My husband was diagnosed with early stage Alzheimer's disease about 1 year ago. While he was relieved to know he wasn't "crazy" he is embarrassed by his changes in memory and thinking. He no longer wants to go out with old friends or take part in favorite activities. This once very strong and confident man is now turning into a quiet hermit who watches TV all day. What can I do to help him stay engaged in life?

Signed,
Liz

Dear Liz,

There is no doubt that getting a diagnosis of Alzheimer's disease is life changing. While most people are relieved to learn that the changes they are having in memory and thinking are due to an underlying illness like Alzheimer's, there is also a recognition of how these changes will impact life now and in the future. Because there is a lot of stigma attached to a dementia diagnosis, there is fear for many that they will no longer be seen as the "person" they have always been. And for many, there is added depression that accompanies the new diagnosis. While there is no single way to make life like it once was, there are certainly many things you, your family and friends can do to help your husband feel accepted, loved and needed in your lives. Consider the following:

- Be sure that your husband and you talk with the doctor about his mood. Report any new or growing signs of apathy (lack of interest); irritability; social isolation; excessive sleeping or trouble thinking. Many people living with Alzheimer's disease have co-existing depression that responds well to medication. Don't be afraid to ask! Depression left untreated will add to his lack of interest and greater confusion.
- Talk with your husband about how the two of you can let important people know about his condition and how they can help. How much information you give to each party may be different. In general, telling others that "I have a medical condition that is affecting my memory and I am getting help. I hope that you will be patient with me when I have problems remembering. I also hope that we can continue to do things together." If he is uncomfortable telling people, you can respectfully reach out to his closest family members and friends and let them know that you would like them to stay connected to him. Be specific about what you would like them to do with him. For example, "I would love if you would go golfing with him every few weeks." "He loves walking in the neighborhood – would you come by and ask him to join you in the afternoon?"
- Have your husband do chores with you around the house. Even if the results are not perfect, he is up and moving and doing his best. Don't point out errors rather, genuinely thank him for his help.
- Avoid putting him in situations where he will fail. Rather, you know what his strengths are so plan activities that support his abilities.
- Include him in making choices and decisions whenever possible.
- Seek out others in a like situation. The Alzheimer's Association offers Early Stage Support Groups for both the person and family. In Tempe, Arizona, each Monday morning from 9:30am – 12N there is a "Memory Café" bringing together people with memory loss and their care partners. Look for an Arts Engagement Program in your area. These are just a few examples in which new friendships can be made.

Recognize that you will need to take an active role to make these strategies happen. Be patient with him and yourself. You are both adapting to living with a new chronic condition.



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, August 10, 2017 from 12:30 – 2:00pm at Banner Alzheimer's Institute, 901 E. Willetta Street, Phoenix, First Floor Education Center.

Dementia Dialogue Webinar: Helping the Person with Dementia Feel Worthwhile.

Join the discussion on Wednesday, August 16, 2017, 12N – 1pm (AZ time). Registration required: www.banneralz.org/dementiadialogues.

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.

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Have a Question?

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





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Helping the Person with Dementia Feel Worthwhile (con't)

Play to strengths:

As a caregiver, you are constantly watching to see what your person needs from you and adapting to meet those changing needs. This understandably, can cause you to focus on the losses. When scheduling activities, it is important to take stock of your person's remaining abilities and focus on them.

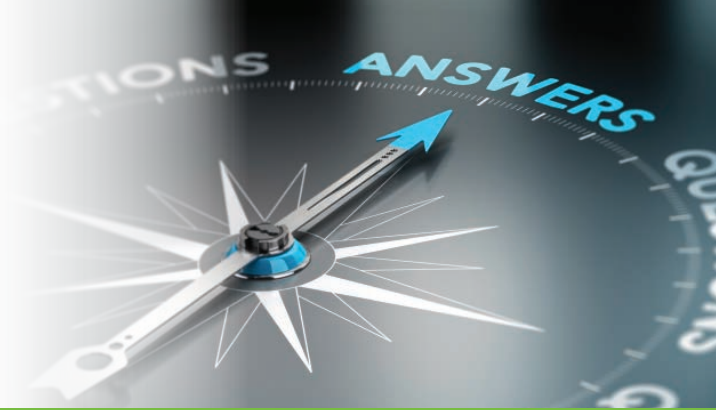
For example, when the person has a short-term memory loss, assistance will be needed with activities that require this skill. However, long-term memory will remain intact for much longer. Rather than focusing on activities that require a thought process they no longer possess, bring tasks that draw upon long term memory and abilities that help them to find success and tap into their strengths. When social skills remain strong, allow them to use them in social settings. Each will bring a sense of worth.

Worthwhile:

While some tasks will be managing day-to-day life, it is of paramount importance that activities are scheduled that contribute to your person's feelings of worth and dignity. When reflecting on the many roles they have played throughout their life, consider how those

roles can be achieved or simulated through the use of modified activities. Helping your person feel they are a valued contributor to their environment is the ideal. While they may not be able to execute the activity independently anymore, try to facilitate in a way that encourages as much autonomy as possible. Show appreciation for what they can do and encouragement when they need assistance. Worth, dignity, autonomy and independence are what humans strive for. Because the person you care for developed dementia, does not change those needs. It changes the ability to attain them. By carefully considering who your person was and is, modifying tasks and playing to their existing strengths, it can help you fill your person's day with meaning and purpose while contributing to their sense of self-worth.





CAREGIVER EDUCATION PROGRAM SCHEDULE

August/September 2017

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. 10, Thurs.	10:00am – 11:30am	Denial: Understanding Why Your Person Doesn't Understand	BAI	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 event/ education and online 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)
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/dementiadialogues
Please note that all webinars are recorded and archived on website 24-28 hours after live session or call 623.832.3248



September

Date	Time	Name of Class	Location	To Register
Sept. 6, Wed.	10:00am – 11:30am	As Dementia Progresses	BSHRI	623.832.3248
Sept. 7, Thurs.	9:30am – Noon	Banner Brain Health Program	BAI	602.230.CARE (2273)
Sept. 12, Tues.	2:00pm – 3:30pm	Emotional Impact of Parkinson's disease	BSHRI	623.832.3248
Sept. 12, Tues.	4:00pm – 6:00pm	Planning Ahead Class for Caregivers	BAI	602.839.6850
Sept. 13, Wed.	9:30am – Noon	Banner Brain Health Program	BSHRI	602.230.CARE (2273)
Sept. 13, Wed.	1:00pm – 2:30pm	Dementia Friendly Presents: Success Stories from Caregivers	Tempe Public Library	602.839.6850
Sept. 14, Thurs.	5:00pm – 7:30pm	Banner Brain Health Program	BSHRI	602.230.CARE (2273)
Sept. 15, Fri.	9:00am – Noon	Free Memory Screening	BAI	602.839.6850
Sept. 19, Tues.	10:00am – 11:30am	Travel: Planning for Success	Mesa Red Mountain Library	602.839.6850
Sept. 20, Wed.	Noon – 1:00pm (AZ Time)	Dementia Dialogues: Carving out Time for Me: How is that Even Possible?	Online	www.banneralz.org under event/ education and online education
Sept. 21, Thurs.	9:30am – 11:00am	The Brain and Body Donation Program at Banner Sun Health Program	PORA	623.207.1703
Sept. 21, Thurs.	10:00am – 11:30am	Help at Home: Support for the Person Living at Home	BAI	602.839.6850
Sept. 26, Tues.	10:00am – 11:30am	After the Dementia Diagnosis (formerly COMPASS)	BAI	602.839.6850
Sept. 26, Tues.	2:00pm – 3:30pm	Finding Meaning While Living with Loss	BSHRI	623.832.3248
Sept. 28, Thurs.	10:00am – 11:30am	Activities: Filling the Day with Meaning and Purpose	BAI	602.839.6850
Sept. 29, Fri.	10:00am – 12:30pm	Learning to Provide Hands on Care: A Skills Lab for Family Caregivers	Foundation for Senior Living Caregiver House	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

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

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

PORA
13815 W. Camino Del Sol, Sun City West
Register at: 623.207.1703

Foundation for Senior Living Caregiver House
1201 E. Thomas Rd., Phoenix
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



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