



## Carving out time for me: How is that even possible?

For caregivers, the question of “how and when do I have time to take care of me,” is THE million dollar question. Much has been written and reported about the importance of caregiver self-care. But for most, caring for one’s self, while caring of another, continues to be one of the biggest challenges in the caregiving journey. The Family Caregiver Alliance reports that family caregivers, regardless of age, are less likely to practice preventive healthcare and self-care.

It is usually not a question of what to do to improve your own health and well-being, but rather a question of *what keeps you from taking care of yourself* as well as you take care of your person.

A first step may well be to recognize the ongoing losses that occur as a result of the dementia diagnosis. Caring for someone with dementia causes stress, overwhelm and a unique grief that occurs when the person with dementia is physically present but psychologically absent or changed from how they once were. Dr. Pauline Boss coined this term “ambiguous loss.” It is a loss that is unclear, has no resolution and has no predictable ending or closure. Ambiguous loss and grief is not often recognized or understood by caregivers or the public in general.

In her book, *Loving Someone Who Has Dementia*, Dr. Boss recommends using paradoxical thinking because caring for a person with dementia is a paradox. This “Both/And”

thinking entails holding two contradictory ideas in your mind at the same time; both of which are true. Instead of thinking that the needs of the person being cared for take precedence over your needs as caregiver, you change your thinking to acknowledge that both sets of needs are equally important. For example: “I need to both take care of my mother AND take care of myself at the same time.” When we can’t change or fix the problem (dementia), the only thing we can control and change is our perception of our new reality. For most of us this requires a new way to think. Instead of “Either/Or” thinking, we begin using “Both/And” thinking toward finding meaning in the sometimes uncomfortable and unresolvable paradox of dementia.

Caring for another and yourself is a balancing act. While the situation cannot be fixed, we can deliberately choose how we live each day. We can make a conscious choice to get our own needs met and take care of our person simultaneously.

Setting goals may be the first step toward carving out time for yourself. Ask yourself, “What are some things that I would like to accomplish in the next three to six months?” Once you answer that question, think of using an action plan as a useful tool toward meeting your goals. The action plan helps you to identify and quantify the specific steps

to get you there. You are more likely to be successful if you break down a goal into smaller manageable steps. For example, list what you will do, how much/how often you will do it, and when you will do it. Then reflect on how confident you are that you will accomplish your plan this week. Use a scale from 0 (not confident) to 10 (7-10 very confident). If your confidence level is less than 7 you may want to adjust your plan as needed.

### Example:

**Goal:** I want to take better care of myself

#### Possible Action Steps:

1. Resume my walking routine: 3 times a week/ for 30 minutes/on Monday, Wednesday, Friday while husband is at adult day program. Confidence level: 8
2. Practice yoga using my video: 2 times a week/ for 20 minutes/ on Tuesday, Thursday, Saturday while mom is napping. Confidence level: 7
3. Schedule a weekly outing for myself: once a week for two hours, with a friend to meet for lunch, shop, or just talk. Confidence level: 9

Self-care may even be important in the prevention of dementia in caregivers. The July 2017 Lancet Commission on Dementia, using 24 international experts, reviewed available evidence and created recommendations about how best to manage or even prevent dementia. The authors suggested that there may be an opportunity to take action and address nine potentially modifiable risk factors that if eliminated, could reduce the incidence of dementia or substantially delay its onset. These risk factors include: low educational level in childhood, hearing loss, hypertension, obesity, smoking, depression, physical inactivity, social isolation, and diabetes. All of these factors are changeable and may be useful as a goal of improved self-care as a caregiver.

However, sometimes we need motivation to take care of ourselves. When we better manage/modify risk factors and stress in life, we not only feel better and more equipped to handle our caregiver role, but this may prevent or delay our own onset of dementia as well. In addition, we know that when caregivers are less stressed, overwhelmed, and frustrated, their person is often less behaviorally challenged. This is an example of "Both/And" thinking-when the caregiver takes care of self, BOTH the caregiver AND the person receiving care win!

The following examples come from real life caregivers who have made conscious decisions to take better care of themselves. Perhaps hearing about what others have found beneficial can prompt your own vision of what improved self-care could mean for you.

A common method of improving self-care is to resume or begin an exercise program. One woman realized that upon awaking in the morning her mind would be flooded with thoughts of tasks to be done, worry of the future, negative thoughts of what she had done or not done. One morning she recalled that she once enjoyed morning walks. Spontaneously she got up, got dressed and went for a walk. She was excited to report to her support group how much better she felt and more prepared to face the day after 20-30 minutes of exercise. This is echoed throughout caregiver groups and individual conversations regarding not only the physical value of exercise, but the emotional and mental value as well. Exercise can be a solitary experience as some prefer, such as swimming, going to the gym, or it can be done in groups that offer social connection such as attending a class or participating in a hiking club.

Another approach is to actively plan and spend scheduled time alone with your own thoughts and emotions toward mindful reflection. Some have described such time as their own "inward search" to allow themselves a chance to listen to their own wishes and needs, to grieve, cry, to acknowledge the ongoing losses that they are experiencing, to imagine new hopes and dreams, and reflect on what remains, what some call "those special moments" of humor, joy, and fun that they continue to share with their person.

A challenge for most every caregiver is battling their mixed emotions of guilt, anger, ambivalence, overwhelm, frustration, and stress. In one group, a caregiver asked "Where do I put my guilt, what do I do with it?" Group members provided amazing suggestions including reframing their thoughts and engaging in positive self-talk. Here are a couple of examples:

- "I think about my feelings as a battery and I know that that batteries need to be recharged when they get low."
- "I am doing the best I can, that is all I can do, I can't do better than that."
- "I remind myself that guilt does not help me or anyone, it uses up my energy. I apologize, make amends, and decide not to do whatever it was in the future."
- "I forgive myself."

One caregiver noted that she is working on normalizing her guilt. She is recognizing that she needs time for herself and is learning to set boundaries about what she can and cannot do.

Caregivers engaged in support groups often describe the group experience as: a safe harbor, a place to vent, to find understanding and support from others and an

**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](http://www.banneralz.org/support-our-mission).



## Ask The Expert

Susy Favaro, LCSW  
Social Worker, Stead Family Memory Center

Dear Susy,

*I don't even know where to start. My mother was diagnosed with dementia several years ago. She lives in an assisted living facility where she gets her meals, her medications, and has the opportunity to participate in a variety of programs and activities; but she chooses not to. She depends on me to visit, take her shopping, manage her finances, and be her constant companion. This doesn't leave any time for me, as I work full time, and with my husband, care for our two children, while managing our own household. I am frustrated, unhappy, have gained weight, and I don't feel like I am doing a good job in any area of my life. How do people do this?*

Signed,  
Jennifer

Dear Jennifer,

You are not alone in wondering how a person cares for themselves while taking care of someone else. It sounds as if your mother is in a safe and supportive environment. I suspect that if she did not have dementia, she would be the first one to encourage you to take good care of yourself. It is not too late to start but it will demand some specific action on your part.

Consider joining a group of caregivers where you can share your frustrations and concerns while learning strategies that others have found helpful. Being with others that are in a similar situation can be restorative and eliminate that feeling of being alone.

I encourage you to ask for and accept help from others. Perhaps your mom has friends or there are family members that would be willing to visit her on a regular basis if they were asked. That could lessen her need to have you as her constant companion. You might talk with the activity coordinator at the facility to determine if there is a specific role or task you mother could take on that would be meaningful to her and helpful to others.

Don't neglect your physical health. If you have put off annual checkups with your doctor or curtailed exercise, make a conscious choice to reinstate them both. Caregivers often find that regular exercise not only benefits them physically but provides a needed mental and emotional boost as well.

Schedule regular time to be with friends and family who support you and you have fun with. Sometimes even a quick phone call or email can give you that connection that makes the rest of your day go better. Periodic time away (alone or with your husband and kids) can be beneficial and allow you to return to your caregiver role with renewed energy, fun stories, and pictures you can share with your mom about your trip.

Please remind yourself every day that you are doing the best you can. You can only do so much. This demands acceptance of a less than perfect situation and you can actively decide as a caregiver to accept that what you are doing IS good enough.



[www.banneralz.org](http://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, September 14, 2017 from 12:30 – 2:00pm at Banner Alzheimer's Institute, 901 E. Willetta Street, Phoenix, First Floor Education Center.

**Dementia Dialogue Webinar: Carving out time for me: How is that even possible?**

Join the discussion on Wednesday, September 20, 2017, 12N – 1pm (AZ time). Registration required: [www.banneralz.org/dementiadialogues](http://www.banneralz.org/dementiadialogues).

If you need to register for audio only, call 623.832.3248.

### SPECIAL EVENT!

**Forget Me Not** play is coming to Phoenix! **FMN** takes the audience into the life of a family facing this Alzheimer's disease and shows its impact on not just the immediate family but friends, marriage, and those in the community as well.

Saturday, Sept. 30, 1-4 pm  
Herberger Theater - Phoenix.

Registration: 202.349.3803

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: [baiinfo@bannerhealth.com](mailto:baiinfo@bannerhealth.com)



## Carving out time for me: How is that even possible? (con't)

opportunity to listen to different ideas and try them out toward gaining a new perspective.

Mixed emotions are to be expected in caring for someone with dementia. It is necessary to manage these feelings in order not to act upon them inappropriately. Talk about and share these feelings with supportive friends, a support group or health care professionals. You need to understand that you are not alone. Take educational classes to learn skills to help manage mixed emotions.

Ask for and accept help from others. Let others show you how much they care. If you are not getting the support you need from your biological family, create a family of choice - a psychological family of people you can depend on. Realize that you cannot get too much help. No caregiver ever says, "I got too much help too soon."

Take regularly scheduled breaks and have **fun**. Fun is a necessary component of effective caregiving. Going out with friends, engaging in activities that make your heart sing and give you pleasure should be a mandatory prescription for every caregiver. It is important to thoughtfully schedule these times away because time can so easily get eaten up by the multiple demands of caregiving. You are not only doing yourself a favor, you

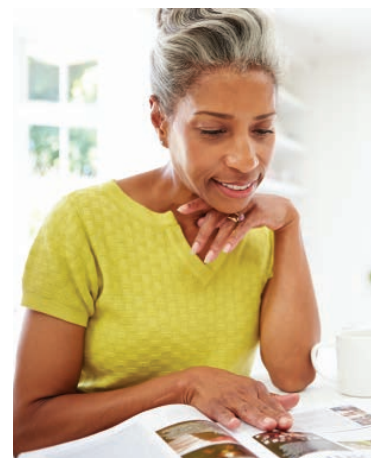
are giving your person an opportunity to see you relaxed and enriched.

Several caregivers have noticed that once they begin working towards improved self-care their enjoyment of their current life improves. One man stated, "My job is to keep my wife safe, happy, and healthy AND do the same for myself."

Another caregiver noted, "I take care of myself through respite weekends, support group attendance, adult day programs for my husband, exercise, a good diet, and sleeping well."

Dr. Boss says it best, "The question of how to be a good caregiver has multiple answers, but taking care of yourself is always one of them".

\*Boss, P. (2011). Loving Someone who has Dementia: How to find hope while coping with stress and grief. San Francisco: Jossey-Bass.





# CAREGIVER EDUCATION PROGRAM SCHEDULE

September/October 2017

## September

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

**All classes are free but registration is required.**

## October

Date	Time	Name of Class	Location	To Register
Oct. 3, Tues.	10:30am – Noon	<b>Residential Care: When moving becomes the best option</b>	Banner Gateway Medical Center	602.839.6850
Oct. 4, Wed.	10:30am – Noon	<b>After the Dementia Diagnosis (formerly COMPASS)</b>	BSHRI	623.832.3248
Oct. 5, Thurs.	4:00pm – 5:30pm	<b>Travel: Planning for Success</b>	BAI	602.839.6850
Oct. 10, Tues.	10:00am – Noon	<b>Planning Ahead Class for Caregivers</b>	BAI	602.839.6850
Oct. 11, Wed.	10:00am – 11:30am	<b>Non-Pharmacological Management of Parkinson's disease</b>	BSHRI	623.832.3248
Oct. 11, Wed.	1:00pm – 2:30pm	<b>Dementia Friendly Tempe Presents: Plan B: When Emergency Strikes a Dementia Caregiver</b>	Tempe Public Library	602.839.6850
Oct. 12, Thurs.	9:30am – 11:00am	<b>Behaviors: Expressing What Words Cannot</b>	BAI	602.839.6850
Oct. 12, Thurs.	6:00pm – 7:30pm	<b>After the Dementia Diagnosis (formerly COMPASS)</b>	BSHRI	623.832.3248
Oct. 16, Mon.	4:00pm – 5:30pm	<b>After the Dementia Diagnosis (formerly COMPASS)</b>	BAI	602.839.6850
Oct. 17, Tues.	10:00am – Noon	<b>Planning Ahead Class for Caregivers</b>	Mesa Red Mountain Library	602.839.6850
Oct. 18, Wed.	Noon – 1:00pm (AZ Time)	<b>Dementia Dialogues Webinar: Role Changes and Reversals</b>	Online	www.banneralz.org under event/ education and online education
Oct. 25, Wed.	10:00am – 11:30am	<b>Emotional Changes: Understanding Symptoms Beyond Memory Loss</b>	BSHRI	623.832.3248
Oct. 30, Mon.	2:00pm – 3:30pm	<b>Medications for Dementia: What are they &amp; What can I expect</b>	BSHRI	623.832.3248

**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

**Banner Gateway Medical Center**  
1900 N. Higley Rd., Gilbert  
Register at: 602.839.6850

**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](http://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](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