



Role Changes and Reversals

After an individual is diagnosed with dementia, and as the disease progresses, his or her role will change from collaborative partner to becoming increasingly reliant on others – usually family members. A spouse or adult child may quickly move into the role of primary decision maker, overseeing financial and medical decisions. Not only do familiar roles change, but it often feels as if the roles reverse. A spouse/partner or adult child watch their person's independence and self-sufficiency turn to reluctant dependency and ultimately surrender. These new and unfamiliar responsibilities may become quickly overwhelming and feel unmanageable, leaving the family member to feel alone. How does a loved one identify, adapt, understand and plan for the changes that affect relationships as the dementia progresses? How do family caregivers handle the changes to their relationships, as they take on more and more responsibilities? How do caregivers process their feelings and emotions related to these changes? And most importantly, how do caregivers take care of themselves?

As we hear from many of our patients and their caregivers, no one is quite prepared for the changes facing a relationship or family system as the dementia progresses. However, there is solace and peace in knowing that a person living with dementia will always carry the label of beloved wife, husband, partner,

sibling or parent, even if their roles, responsibilities and functions require more assistance. It is the person's ability to care for themselves and for you as a family member that changes. This can be difficult to manage. However, it is planning for and acceptance of these changes that provides caregivers with the potential to still love the person as they were, while accepting the progression of the disease and looking for intact abilities and new possibilities for connection.

Often it is the handoff of roles and responsibilities that can be most frightening and emotionally challenging. Perhaps the relationship had been well defined throughout the years, but now you find yourself taking on unfamiliar tasks such as managing finances or taking on tasks at home such as cooking, cleaning, home maintenance, etc. Or perhaps you are now doing all the driving or future planning for the very first time. Some family caregivers find they need to work again in order to pay for needed care, while others have to give up their jobs in order to provide more supervision and care at home.

Many face these role changes with natural resistance and understandable fear and anxiety. It is not uncommon for caregivers to express that they were unprepared for these changes – even in the face of growing older. Many families have not had important conversations about handling health care, financial and legal decisions. So

this new role of having to make decisions and take on new roles as the person can no longer do so, feels uncomfortable.

Adult children of those living with dementia may face more sudden added responsibilities. As an adult, you may have lived apart from your parents and didn't fully understand the severity of the dementia progression or that your parent was in need of that much help. You may not have even seen the symptoms as clearly as other family members and may have a level of denial. You may have to ask for additional help from those who still don't grasp the level of progression mom or dad is exhibiting (including other siblings). You may be handed the role and responsibility of assuming care or oversight for a parent with or without any other family support. Or perhaps your relationship with your parent has always been strained and now you are reluctantly charged with their everyday care and legal and/or financial oversight. Not only do you have to address the growing responsibilities for their care, you must also come to terms about not wanting the role at all. Furthermore, as the person with dementia declines, an adult child may find that their role becomes to "parent their parent". This requires skilled adaptation and can result in greater feelings of loss and role confusion. A spouse may find she feels more like a caregiver than a wife when her husband can no longer reciprocate the emotional support they once shared.

In addition to the natural fear and unfamiliarity of now fulfilling these roles and responsibilities, caregivers will see less participation from their person as their disease progresses. It is a challenge to take on the role of managing your person's everyday safety and security from the management of medication to daily hygiene and nutrition to protecting her from becoming vulnerable to those who may take financial advantage. The responsibilities can be daunting and exhausting.

In some relationships, the person with dementia may have always played the role of the family "rock," the one everyone always turned to for direction, advice, decision-making, financial oversight and future planning. Or perhaps s/he laid the foundation for the family traditions and holiday planning and kept the family together and emotionally intact. These changes create a sense of grief, loss and sadness for caregivers and a heightened sense of anxiety when trying to take on these new roles or maintaining traditions.

To make matters more difficult, the person with dementia may be reluctant to relinquish those familiar,

yet increasingly, difficult tasks and resist the caregiver's "interference." As much as the person wishes they could still continue these roles, their ability is quickly diminishing. Knowing that they can no longer safely drive or manage their own finances is sometimes the very last concession a person living with mild to moderate dementia will make. Getting around or coming to that realization and shifting the control is often a struggle. Recognize that for many people with dementia, they have little insight into the changes they are experiencing.

It is important to note that role transitions with early stage dementia present subtle changes in day to day communication and socialization activities as many people remain mostly independent in their care. Role changes may go unnoticed by friends and family and therefore, little assistance or support is offered. Roles seem intact and changes may not be easily detected within social circles. A caregiver may find him/herself taking on more of a significant role in the relationship, while not yet fully assuming the majority of responsibilities. As the disease progresses, the caregiver assumes greater daily oversight and more significant role changes begin to emerge. This can trigger caregivers to realize their own limitations and even recognize the previous division of responsibilities and tasks that existed in their relationship. The caregiver may begin to withdraw socially and as s/he experiences emotional and physical fatigue that accompanies the role change and expanded responsibilities. This may be when caregivers begin to truly feel the "loss" of their spouse/partner or parent. A wide variety of emotions are experienced that include anger, guilt, anxiety and sadness – all of which are normal and expected.

There are multiple changes not only for the person living with dementia, but also for those who love and care for them. It is important that caregivers acknowledge and proactively plan how the needs of their person will change and grow. In addition, caregivers must also embrace the inevitable changes in the ways to interact with their person. S/he will require more and be unable to offer mutual support.

In your emerging role as caregiver, it is essential to find new opportunities to receive your own emotional support and care; finding others who can identify and assist in finding solutions. It is equally important to hold strong to the belief that the core being of your roles will not change: a spouse will always be a spouse, a parent will always be a parent, despite the shift in the relationship.

Looking for a way to make a gift to Banner Alzheimer's Foundation without spending your cash?

A charitable bequest is a wonderful way for you to help further the work of Banner Alzheimer's Foundation and its mission of delivering care and hope to families while advancing research. For more information, please contact us at (602) 747-GIVE (4483) or plannedgiving@bannerhealth.com.



Ask The Expert

Shannon Arriola

Outreach Program Manager, Banner Sun Health Research Institute

Dear Shannon,

I have been with my wife and partner, Shirley for 30 years. It took me a while to realize she had developed dementia as it seemed to creep up slowly. Now I find myself as her caregiver. Don't get me wrong, I adore her and would do anything to help her, but I am struggling with the idea that she is no longer the same person. I feel guilty in admitting it, but I miss our old life. I never quite realized how much she took care of things around the house, our social life, and finances. Now all of those responsibilities fall on me, along with managing all of her medical appointments, helping her bathe and dress, the list is long. I miss the closeness we shared and the support and laughter she brought into our relationship. I am embarrassed to say I often feel more like her parent than her partner. How can I manage the change in our roles without going crazy?

Sincerely,
Pat

Dear Pat,

I am glad you are able to share these complex yet common feelings. I also appreciate your honesty about the changes that occur with emotional and physical intimacy. It is normal to experience a range of emotions and even grieve the loss of your prior relationship. Role changes are common when a spouse or partner becomes a caregiver. Despite best intentions, the person with dementia is no longer able to offer the same kind of emotional support, help around the home, maintain social and family connections or manage hygiene independently. It is wonderful to hear you are so dedicated to her care, but it is important for you to take care of yourself as well. We often become so lost in our caregiving role, that our own emotional and physical health becomes compromised.

Here are some tips to allow you to more adequately manage the change in your roles and relationship:

- Acknowledge the change in your roles and relationship with honesty and clarity. Allow yourself time to grieve the changes and accept that the roles will continue to change as you both adapt to the progression of the disease.
- Try to accept that despite the disease, you will **need** and **deserve** to receive emotional support. Seek a caregiver support group, close friend or a professional nurse, counselor or social worker you can confide in and process your feelings.
- Try to maintain an emotional and physical connection with your wife despite the progression. You may find holding hands, hugging or cuddling feels good or reading aloud, sharing positive memories from the past, listening to music together or prayer or spiritual rituals may offer comfort. Laughing together is a wonderful form of intimacy.
- With your support, try to involve your wife in some of the household tasks she once managed so she can continue to feel engaged even if things aren't done perfectly or take longer. Remember to be patient, supporting and encouraging as she tries to participate.
- Find ways for you both to stay socially connected and stimulated with small groups of friends or family, local adult day health programs or life enrichment programming.

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

Dementia Dialogue Webinar: Role Changes and Reversals

Join the discussion on Wednesday, October 18, 2017, 12N – 1pm (AZ time). Registration required: www.banneralz.org/dementialogues. 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.

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





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Ask the Expert (con't)

- Continue to enjoy some of the common interests you shared before with modifications. Try watching a baseball game rather than heading to a crowded ballpark or listening to your favorite music and dancing at home with a small group of friends.
- Ask for and accept help with the care. Many friends and family members may be willing to help support you, but they likely don't know what you need. Be specific in your requests and look out for additional resources of volunteer or fee for service agencies that offer additional services to lighten your load: home delivered meal programs, volunteer visitors or in-home professional caregivers.
- Continue to make memories together for you and your person to cherish.

Remember that despite your change in roles, caregiving can offer an extremely rewarding experience for you as the caregiver and likely is greatly appreciated by your partner, whether or not she is able to express it.





CAREGIVER EDUCATION PROGRAM SCHEDULE

October/November 2017

October

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

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

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/dementiadialogues
Please note that all webinars are recorded and archived on website 24-48 hours after live session or call 623.832.3248

All classes are free but registration is required.

November

Date	Time	Name of Class	Location	To Register
Nov. 1, Wed.	10:00am – 11:30am	Planning Ahead	BSHRI	623.832.3248
Nov. 3, Fri.	9:00am – Noon	Free Memory Screening Event	BSHRI	623.832.3248
Nov. 7, Tues.	10:00am – Noon	As Dementia Progresses: Next Steps for Caregivers	BAI	602.839.6850
Nov. 8, Wed.	10:00am – 11:30am	Finding Meaning While Living with Loss	BSHRI	623.832.3248
Nov. 8, Wed.	Noon – 1:00pm	Parkinson's Pre Screening Lecture	BSHRI	623.832.3248
Nov. 8, Wed.	1:00pm – 2:30pm	Dementia Friendly Tempe Presents: Helping Caregivers Find Meaning While Living With Loss	Tempe Public Library	602.839.6850
Nov. 9, Thurs.	6:00pm – 7:30pm	Denial: Understanding why your person doesn't understand	BSHRI	623.832.3248
Nov. 10, Fri.	1:00pm – 3:30pm	Banner Brain Health Program	BAI	602.230.CARE (2273)
Nov. 13, Mon.	10:00am – 11:30am	After the Dementia Diagnosis (formerly COMPASS)	BAI	602.839.6850
Nov. 14, Tues.	1:00pm – 3:30pm	Banner Brain Health Program	BSHRI	602.230.CARE (2273)
Nov. 14, Tues.	4:00pm – 6:00pm	Planning Ahead Class for Caregivers	BAI	602.839.6850
Nov. 15, Wed.	10:00am – 11:00am	Talk with the Doc: Dementia Q & A with Expert Dr. Spann	BSHRI	623.832.3248
Nov. 15, Wed.	Noon – 1:00pm (AZ Time)	Dementia Dialogues Webinar: Facing Financial Issues: Is the Rainy Day Here?	Online	www.banneralz.org under event/ education and online education
Nov. 16, Thurs.	10:00am – 11:30am	Residential Care: When moving becomes the best option	BAI	602.839.6850
Nov. 17, Fri.	9:00am – Noon	Free Memory Screening	Pyle Adult Recreation Center	602.839.6850
Nov. 21, Tues.	10:00am – 11:30am	Denial: Understanding why your person doesn't understand	Mesa Red Mountain Library	602.839.6850
Nov. 22, Wed.	9:00am – 10:30am	Travel: Planning for Success	BSHRI	623.832.3248
Nov. 29, Wed.	10:00am – 11:30am	Activities: Filling the Day with Meaning and Purpose	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

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

Pyle Adult Recreation Center

655 E. Southern Ave., Tempe
Register at: 602.839.6850

Dementia Dialogues Webinar Series

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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

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Banner Alzheimer's Institute
Banner Sun Health Research Institute