



BAI Beacon

The Newsletter from Family and Community Services

www.banneralz.org

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The Experience of Grief and Loss in Caregiving



Caring for a person with Alzheimer's disease or related dementia is an emotional journey for most family caregivers. It is often described as a time that creates high levels of stress, anxiety and even depression. We now understand that for many, grief and loss is at the core of this experience. If we overlook grief issues that occur throughout the course of the illness, it may lead to a more complicated healing process following the death of the person with dementia.

When thinking about the experience of grief and loss, it is normal for people to have a variety of thoughts, feelings, physical sensations and behaviors. As the diagnosis of Alzheimer's/dementia is made, caregivers may begin to think about losses they are likely to experience both now and in the future.

Over the course of the illness, caregivers are likely to experience:

- Feelings of personal sacrifice in order to meet the person's needs.
- Personal sadness about the impact of the disease on the person.
- Longing for the relationship and the person they once knew.
- Depression-like sense of uncertainty.
- Feelings of isolation or withdrawal from others.

We have also learned that the grief experience will change over the course of the illness and will be different depending on the caregiver's relationship to the person with dementia. During the early or mild stage of dementia, spouses are likely to experience sadness but continue to focus on their shared activities and the relationship. At this same time, adult children have minimal grief and are focused on meeting the most immediate needs of the parent and helping him/her stay as independent as possible.

As the disease progresses to the moderate phase and the person now needs more hands on care, the grief experience intensifies for both spousal and adult children caregivers. In spouses, grief builds and the daily caregiving needs can start to become overwhelming. However, most spouses respond with feelings of compassion, sadness, and frustration as they redefine their relationship as a caregiver. Most will find meaning and encouragement in small successes but are likely to put off discussions of future changes. For adult children, the grief experience is often the most intense during this stage of the illness as the adult child tries to care for the parent, maintain their own home and family, and juggle work demands. Common reactions from adult children may result in anger, guilt and resentment because of their own personal sacrifices in caregiving. Most will cope by getting through one day at a time.

(Continued)



Beacon Bits

BAI offers four free unique Support Groups:

Circle of Friends meets the second Thursday of each month from 12:30 – 2 p.m.

Adult Children Group meets the last Tuesday of each month from 5:15 – 6:30 p.m.

FTD Group meets the second Tuesday of each month from 12:30 – 2 p.m.

Men Who Care meets the first Wednesday of each month from 7:30 – 9 a.m.

All groups meet in the BAI third floor conference room. No registration is required.

Upcoming Workshop:

Memory Assistance and Planning Session (MAPS) for Moderate Dementia is coming up on Friday, March 23 from 8:30 a.m. – 3:30 p.m. at the Foundation for Senior Living Caregiver House, 1201 E. Thomas Road, Phoenix. This full day workshop will prepare family

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When advanced dementia comes and the person is now fully reliant for care, the grief experience for spousal caregivers often peaks in intensity. And, while many families will now need to seek care for their loved one in a residential setting, spousal caregivers may not feel the relief even when turning over care demands. Feelings of sadness, uncertainty and loneliness are common. Adult children will also have high levels of grief during this time, but their feelings of anger and frustration give way to a sense of sadness and regret. Many adult children cope by trying to find new ways to connect to their parent or by having a sense of a final loss.

Grief and loss is rough and complicated but there are many things that can help caregivers cope with these issues. It is essential all family caregivers receive emotional support throughout the illness. For many, routinely attending a support group will provide ongoing education, support and new friendships with others in like situations. For others, it may be a best friend, sibling, spiritual leader, or other confidant who provides nonjudgmental listening and encouragement. Some caregivers find journaling their thoughts and feeling to be very therapeutic.

Since the physical demands of care grow over time, it is important that caregivers allow themselves time for respite, maintaining relationships, and good self-care. Respite may be found in a friend, family member, volunteer or paid caregiver to stay with the person or by utilizing an Adult Day Health Care program. While every family caregiver dreads to think about moving their loved one to a residential setting, it is often helpful to think ahead should that care become necessary. Much of the uncertainty comes when caregivers don't know what to expect. Getting educated about the disease and the care options can provide a sense of relief for many.

Finding new ways to stay connected to the person can be challenging but equally rewarding. Since long term memories are most robust, this is a great opportunity to take time to reminisce and hear favorite stories. Recording those stories can even be more precious for the years to come. The memory for music is the last to be lost in dementia, so playing favorite songs can reignite memories and allow the person to sing along. Looking through old photo albums or finding picture books that represent the person's interests allow for fun discussions.

While many people think about attending grief and bereavement groups following the death of a loved one, many caregivers have benefitted from these groups while the person is living. New skills can be learned, caregivers can be reassured that their feelings are normal, and there is hope for the future.



Ask The Expert

Joan Keffeler
BAI Volunteer

Dear Joan:

My mom has had Alzheimer's disease for the past six years and it has been tough watching this slow decline. While there are three children in the family, it seems that I am the one who helps my dad. However, I am getting tired and find that I am resenting my siblings more and not enjoying the time with my mom like I should. How can I move beyond this?

Signed: Deflated

Dear Deflated:

As a daughter of a mom with Alzheimer's, I certainly feel your pain and have come to accept the quote, "It is what it is" related to my mom's condition. However, I made a decision that I would create and share in the moments with my mom while making it fun! I began to ask myself, "What did mom and dad love to do together and how could I make some of those things happen?" What resulted was me focusing on having "fun" versus the "chore" of caregiving – and seeing my mom have fun. Since my folks were very social, when my mom and I go out to eat, we sit at the restaurant bar so we can talk to others around us. Because they loved to travel, I take my mom on short car rides where we can enjoy the scenery and reminisce at the same time. She loved going to church and so I make sure we do that together as it brings both of us joy. Mom was busy raising seven of us, so I enjoy baking cookies with her, ask her to help me fold the laundry or dry the dishes. While she might not do these "chores" perfectly any longer, she feels needed.

One of the biggest lessons that I have learned is that I have to accept that my siblings and other family members may not accept mom's illness the same way I do and I can't pass my expectations off on them. I can only control me. I chose to spend time with mom and focus on fun and look for the possibilities in her rather than focusing on the losses. Don't get me wrong, I miss the mom I knew, but I am so grateful for sharing fun moments with her now!

caregivers on what to expect and how to care for dementia as it progresses to the moderate and advanced stages. This highly rated workshop has limited seating so call (602) 839-6850 or email Deidra. Colvin@bannerhealth.com to sign up today!



Upcoming Fun:

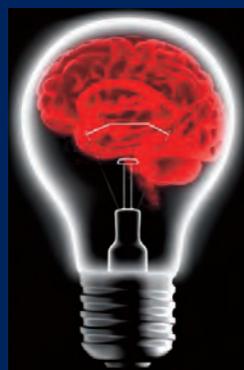
Making Music, Making Memories brings together people with memory loss, caregivers and staff from ASU College of Music Therapy, City of Tempe and BAI as we make and enjoy music together. Join us at our new location, Pyle Adult Recreation Center, 655 E. Southern Avenue, Tempe. We meet on the first Friday of every month from 10 – 11:30 a.m. No registration required and the program is FREE.

Arts Engagement Program is now enrolling participants with dementia and their caregivers to enjoy a series of interactive docent-led tours at either the Phoenix Art Museum, (602) 257-1222 or the Scottsdale Museum of Contemporary Art, (480) 994-2787. These programs are offered quarterly and offer a fun and intimate look at art.

Brain Health Tip:

Reading aloud or listening to someone read impacts different parts of the brain than when we read silently.

Since reading is an important mental activity, try reading aloud with a partner. Have one person be the reader and the other the listener. It might take longer but you will engage more neurons and likely have more discussion with your partner!



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.

Have a question?

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