



BAI Beacon

The Newsletter from Family and Community Services
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Intimacy and Dementia

Even hearing the word "intimacy" can often make people uncomfortable, let alone talking about it. Yet it is an issue that surfaces in many ways in the journey of dementia, impacting relationships and adding challenges to the caregiving role.

For many of us intimacy means emotional and physical closeness; warmth, comfort, trust and sharing; vulnerability. It is of a private or personal nature. To have intimacy, there must be good communication.

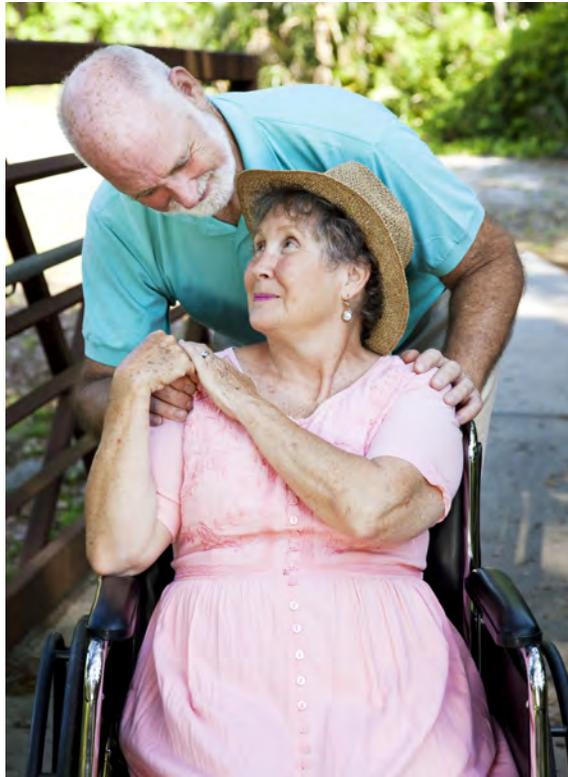
Intimacy refers to our sense of commitment or connection, to our sense of caring for, having thoughts about and awareness of another. These might be viewed as emotional intimacy. There is also the physical aspect to intimacy, which can range from gestures of affection to sexuality, all involving a sense of mutual interest and participation.

Intimacy and sexuality are basic human needs, not diminished with aging, although sexual abilities and interest may fall off. Having intimacy in one's life adds to happiness and a sense of well being. This comes from shared trust, communication, touch, humor and positive regard.

Alzheimer's disease and other dementias do not affect just memory, but thinking, mood and behavior as well. Communication becomes affected with time, limiting the dialogue or conversations that we rely upon to create a sense of verbal intimacy and trust, to know what the other is thinking or feeling. People with dementias gradually lose their empathy, their outwardly directed concern for another's well being, appearing more thoughtless and selfish, no longer initiating expressions of love.

They may not remember or recognize a person caring for them, or may misinterpret who that person is and avoid them. They may not remember how to engage in sexuality. Their sexual needs may be expressed in ways that create conflict for family or spouses; for instance, losing their inhibitions and acting inappropriately. Such behaviors may include disrobing in public, or acting uncharacteristically flirtatious or suggestive. Some with dementia may become hypersexual, directing their energies towards other people or in inappropriate places, or demanding that a partner meet their needs constantly. They may accuse partners of infidelity. As some become more childlike in their demeanor, they may have no interest in any aspect of sexuality. Whether a person with dementia can continue to be considered a consenting adult creates a dilemma as well.

(Continued)



Beacon Bits

First Friday Making Music, Making Memories Session
Friday, Feb. 1, 10 – 11:30 a.m.
Pyle Adult Recreation Center
655 E. Southern Avenue, Tempe
Registration: (602) 839-6850 or
Baiinfo@bannerhealth.com

GPS: Important Discussions & Decisions Faced during Dementia
Learn how to understand and strategize the numerous medical, social, financial and legal decisions that will be faced from diagnosis to end of life.

Friday, Feb. 8, 10:30 a.m. – noon
Banner Sun Health Research Institute
Building B, Morin Auditorium
10515 W. Santa Fe Drive, Sun City
Registration required: (602) 230-CARE

Planning Ahead Class for Caregivers
Monday, Feb. 11, 10 a.m. – noon
Banner Alzheimer's Institute,
Third Floor Conference Room
901 E. Willetta St., Phoenix
Registration: (602) 839-6850 or
Baiinfo@bannerhealth.com

Memory Screening Event
Tuesday, Feb. 19, 9:00 a.m. – 3:00 p.m.
Banner Alzheimer's Institute,
Third Floor Conference Room
901 E. Willetta St., Phoenix
Registration required: (602) 230-CARE



While we can better understand how changes in the brain and the disease process can impact intimacy and sexuality for a person with dementia -- what can be said about the care partner's needs or concerns? For some there is a great sense of loss and grief with changing intimacy in the relationship. Others may feel anger or resentment. Many care partners find their own interest waning as their role becomes more involved and more tiring. They may themselves feel less attractive, and less attracted to their partner. They may have ambivalence, feelings of guilt related to refusing advances, or to wanting life to be different, to not always sacrifice their own needs in caring for their loved one. Certainly resentment can build in response to accusations made against them, or to the behaviors described above, particularly when they may feel others are holding them accountable for such behaviors. Lastly there can be frustration related to problems arising during sexuality and to dealing with day-to-day challenges.

Aside from sexual intimacy, there are ways in which intimacy can become a problem. Adult children are often caregivers for a parent. They too experience the loss of emotional intimacy, the embarrassment or confusion related to inappropriate sexual behaviors, to not being recognized for who they are. They, as well as spouses, may not be comfortable in having to provide physical care; helping the person with dementia dress, bathe and toilet. This is also not always comfortable for the person with dementia, so combativeness often arises at a time when more physical help is needed.

It is important to recognize that a change in intimacy can create conflict and become an issue in advancing dementia. However, talking about it can help you gain perspective and find ways in which intimacy can be honored that allows for comfort on both sides. Talking about it with your doctor or social worker can help you deal with your feelings, and can help develop strategies by which to address behavioral aspects, as well as how to maintain a loving relationship.

As always, remembering that behaviors are forms of communication and identifying the situations in which they occur will be important. For example, what appears to be disrobing inappropriately may actually signal a need to toilet. All of the general guidance in approaching behaviors holds true: know the triggers, anticipate needs, distract and redirect the person's attention and consider practical solutions. Most importantly, remember the very human need for contact and comfort. Provide physical attention through hugs, rubbing the back, stroking the hair, holding hands and communicating reassurance through your voice.

Finding a way to hold sight of the positives in your relationship will help guide loving interactions, no matter how advanced the dementia is. Nurture those aspects through touch, through singing, looking at photo albums and reminiscing, sharing prayer. In those moments you will also find comfort for yourself.



Ask The Expert

Helle Brand, PA
Physician Assistant

Dear Helle:

I miss the intimacy of our relationship. I can't remember when my husband last said my name, or reached out to give me a hug or a kiss. It makes me so sad to see him this way. What can I do?

Sharon S.

Dear Sharon:

I can feel the sense of grief and loss you are experiencing. I want you to know that what you are feeling is experienced by many care partners of those with dementia. You have had to adjust to a diagnosis that is difficult to hear, to seeing gradual loss in your husband's memory and function; and experienced also the loss of your hopes for retirement, your sense of your relationship; and likely even your sense of connection with others.

You are brave to ask the question you do, and I commend you for that because it is in reaching out that you can gain insight and find answers that might help you. First and foremost, I want you to make sure that your mood and spirits are in a good place; and that depression is not worsening the situation, making it harder for you to view things with any degree of objectivity or with a positive outlook. I want you also to know that as a care partner it is very important that you keep some balance in your life and not devote all of your energy to taking care of your husband. This means that carving out some time to fill your spirit - your emotional reservoir - with things that have meaning to you, energize or refresh you, or calm you, is very important. When you are in a good place it is easier for you to see things differently, and to bring new energy to being a care partner.

Focus on the qualities that attracted you to your husband, and find those in him now. Was he funny and can you find a way to tickle that funny bone? Was he creative and you can share looking at art, or painting something together? Was he a good dancer or musician, and you can connect through music? Was he a good father, and you can sit and talk about memories of the kids growing up while you look at picture albums together?

Remember the power of touch, and do loving things such as stroke his hair, or his arm, hold his hand. He may not remember your name, but he will connect with your spirit. I love the quote "the mind forgets but the heart remembers."

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

COMPASS Class for Caregivers

Thursday Feb. 21, 10 – 11:30 a.m. OR
Monday, Feb. 25, 4 – 5:30 p.m.
Banner Alzheimer's Institute,
Third Floor Conference Room
901 E. Willetta St., Phoenix
Registration: (602) 839-6850;
Baiinfo@bannerhealth.com

MAPS Workshop

Helps caregivers provide hands on care to someone with moderate to advanced dementia

Friday, Feb. 22, 8:30 a.m. – 3:30 p.m.
Foundation for Senior Living
Caregiver House
1201 E. Thomas Road, Phoenix
\$40 pp/BAI Families, \$60 pp/
Non BAI Families
Registration required: (602) 839-6850
or Baiinfo@bannerhealth.com

GPS: Staying Afloat with the Changing Roles and Relationships in Dementia

Discover adjustments you may need to make to preserve relationships, while maintaining a sense of self and well-being.

Friday, March 8, 10:30 a.m. - noon
Banner Gateway Medical Center
1900 N Higley Road
Gilbert, AZ 85234
Registration required: (602) 230-CARE

Monday STAR

(Sessions to Add Resilience)

Series 1) Feb. 4-Feb. 25, Series 2)
March 4-March 25

Choose from one to three sessions for person with memory loss including cognitive engagement, movement, and/or With Art in Mind. Care partner session provides strategies to maintain resilience as a caregiver.

Morning: 9:30 a.m.-11:30 a.m.;
Afternoon: 1 p.m.-2:30 p.m.

For more detailed information and registration for Monday STAR, call (602)839-6850

Brain Health Tip:

Hugging is not only an extremely positive form of communication but it also expresses love, approval, gratitude and forgiveness. Hugging not only feels good but has some amazing health benefits! Some studies report that hugging reduces blood pressure thus improving heart health. Other studies show hugging can make you happier and more relaxed. Finally, when you hug someone, your brain releases the hormones serotonin and dopamine that can make you feel good and lift your mood.

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.