



BAI Beacon

The Newsletter from Family and Community Services
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Conquering the Struggle at Home

In care classes and support groups, families of people with dementia frequently comment on the emotional struggles they face on a day to day basis. While some of these struggles are listed below, the list doesn't begin to scratch the surface for many family caregivers. Common concerns include:

- Feeling the need to control what happens to your loved one in order to minimize the his/her awareness of their losses;
- Trying to stop correcting your loved one's mistakes and mis-perceptions;
- Managing the tension when your loved one says you are controlling;
- Feeling that you should get family members to respond differently to changes in your loved one by visiting, providing help and/or support on a regular basis;
- Struggling to balance telling the truth with the need to avoid confrontation triggered by truth-telling;
- Maintaining a semblance of the social and personal life you enjoyed prior to the onset of dementia;
- Reminding yourself that you love this person despite whom they have become; and
- Maintaining a sense of self despite the length and ongoing demands of the disease process.

Caregivers report a variety of ways to cope with their struggles by: attending classes and support groups; not attending classes and support groups; going out with friends; going to the movies; exercising; reading; and a whole host of other activities. In addition, there seems to be a few things that families can do that lead to successful coping strategies.

First, admit to yourself that you are feeling the struggle and that it will likely continue to be an issue throughout your person's illness. Admit that, while valiant, caregiving is not always easy. Because your loved one's symptoms are expressed as behaviors, you must recognize the struggle you face to try and understand what is going on. Learning to live with a lack of predictability is easier for some than others. With dementia there is often little you can actually control. Once you have admitted this to yourself, you are in the position to make a plan.

Next, let go of things over which you have no control. If family members are not responding the way you would like, tell them how you feel and then let it go. If you need more help, talk with a confidant, counselor or spiritual leader who will provide non-judgmental listening. You can also talk with the Family and Community Services team members to help you find what will work best for you.

Make plans to take care of you and avoid listening to anyone else's "you should" list. Feel free to say "no" to well-meant suggestions. If you love to exercise, go for it, but if you de-stress by escaping into a novel or craft project - follow your passion. Interests may change over time, so don't be afraid to try something new for you. If the disease lasts another 10 years, you will probably need to try a variety of things

(Continued)

Clinical Trials Announcement

Have you noticed a gradual decline in your memory over the last 12 months? Has this also been observed by someone close to you? Are you between the ages of 50 and 86 years of age? If so, you may be able to help us in the SCarlet RoAD study.

By enrolling in the SCarlet RoAD study you could be given an investigational drug that may improve your memory, or stop it from getting worse. You will receive all research study medication and medical monitoring for a period of about 2 years and 5 months. Contact the (BAI) research study team at 602-839-3111 or visit www.scarletroadstudy.com.

Beacon Bits

Support Group For Lewy Body Dementia & Related Conditions

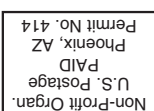
Friday, April 5, 12:30 – 2:00 p.m.
Banner Alzheimer's Institute,
Third Floor Conference Room
901 E. Willetta St., Phoenix
Registration: (602) 839-6900
or Baiinfo@bannerhealth.com

GPS Lecture: When Will We Find Effective Treatment for Alzheimer's Disease

April 12, 10:30 a.m. – noon
Ahwatukee Recreation Center
5001 E. Cheyenne Drive, Phoenix
Registration required: (602) 230-CARE

Banner Health
901 East Willetta Street
Phoenix, AZ 85006

Banner Alzheimer's Institute



that will suit your situation or circumstances. Be selfish with your “me” time. If it means hiring someone to come in to provide respite or sending your person to adult day programming, do it. This will provide you the stamina to continue as the disease progresses. And never underestimate the value of good help.

Finally, recognize common symptoms of depression: crying, irritability, feeling hopeless or useless, eating and/or sleeping more or less. If any of these symptoms persist for two weeks or more, you must seek out medical treatment from your primary care provider. There is no shame in needing help from medications or a counselor. And, there is even less shame in admitting that you can't make it through your loved one's dementia without help. Admitting your struggles and finding help are important skills to make it through the dementing illness.



Ask The Expert

Susy Favaro, LCSW
Social Worker

Dear Susy:

Since my dad died a year ago, I have become increasingly involved in my mom's care. I am trying to let her live in her home for as long as possible by having her attend Adult Day Care while I work. However, I am at her house every morning making sure she has breakfast and takes her medications and then I go back every evening to make sure she has eaten dinner and know she is safe for the night.

While my husband and kids are supportive of my endeavors to take care of mom, I am beginning to feel very overwhelmed. I'm not sleeping well at night and feeling angry about what this situation is doing to both mom and me. I don't want to resent my mom but quite honestly I feel trapped as I don't have any siblings to help me out. What can I do to help both mom and me?

Signed:
Lynn

Dear Lynn

As I read your letter I am stuck by the significant losses that you have experienced in this past year. Your dad died and then you were immediately thrust into the position of primary care partner to your mom. I am so impressed by your follow through on creating a structured routine of adult day health programming for her. However it sounds as if now, the additional support of morning and evening oversight is becoming overwhelming.

Lynn, caregiving can be so rewarding but it is also hard work! Our emotions serve a purpose. They can be a message to us that something needs to change. Challenging emotions such as anger, feeling trapped, overwhelmed, and resentful can provide an opportunity for us to ask ourselves: What is wrong? Why do I feel this way? What can I do about it/ what can help? Feelings aren't good or bad- they just are. How we respond to our feelings and the messages that they send can make a difference in how they affect us. We can decide to respond to the challenges that life throws at us.

The following activity is from the Caregiver Helpbook/ Powerful Tools for Caregivers (Legacy Caregivers) and can be helpful toward problem solving and addressing the messages in the emotions that you are feeling.

- Identify the emotion; ask yourself: What am I angry about, what am I resentful about?
- What can I do about it? (List all the possible solutions as in brain storming. Don't evaluate or judge your ideas; the goal is to create as many options as possible).
- Weigh the pros and cons of each listed option. How would this action benefit you and others, what would it cost you and others?
- Choose an option to try.
- Commit to putting the idea into action by creating an action plan. An action plan is an agreement /contract that you make with yourself. It is something that you want to do- not something you feel you have to do or should do. It is reachable, it is realistic, something that you can accomplish within a week, and answers the questions: 1) What am I going to do? 2) How much will I do? 3) When will I do it? 4) How often will I do it?

An example from your description might look something like this:

1. I am going to explore help that can come into mom's home morning and/evening to attend to her needs (what I am going to do).
2. I am going to schedule two time periods into my weekly calendar to start making calls to find the help needed (how much you will do).
3. I will schedule time on Monday afternoon and Friday morning (when you will do it).
4. I will schedule a half hour time segment on each of these days (how often you will do it).

Although this might appear overly detailed, it encourages you to plan for and schedule your intended action to allow for success. What you are feeling can spur you on to change what is not working for you at this time. Good luck with your new plan – I am confident that you can make it work!

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

MAPS (Memory Assistance & Planning Session) Workshop

Family caregivers learn important hands-on techniques to care for someone with moderate to advanced dementia.

Tuesday, April 16

from 8:30 a.m. – 3:30 p.m.

Banner Alzheimer's Residence

12750 Plaza del Rio Blvd., Peoria 85381

Cost is \$60.00 per person and includes breakfast, lunch, materials, lecture, resources and skills lab.

Call (602) 839-6850 to register

COMPASS Class for Caregivers

Thursday, April 18, 10 – 11:30 a.m.

OR Monday, April 29, 4-5:30 p.m.

Banner Alzheimer's Institute,

Third Floor Conference Room

901 E. Willetta Street, Phoenix

Registration: (602) 839-6850;

Baiinfo@bannerhealth.com

Planning Ahead Class for Caregivers

Thursday, April 18, 10 a.m. – noon

Banner Sun Health Research Institute

10515 W. Santa Fe Drive, Sun City

Registration required: (602) 230-CARE

Broadway Salute Musical

North Valley Chorale, BAI's newest community arts partner, invites 40

BAI Family and Friends to enjoy a free concert featuring an evening of singing and dancing to your favorite Broadway melodies. Additional discounted tickets available by calling 602-464-4100.

Mention BAI for your discount.

Friday, April 26 or Saturday, April 27

Memorial Hall at Steele

Indian School Park

300 E. Indian School, Phoenix 85012

Registration: (602) 839-6850;

Baiinfo@bannerhealth.com

GPS Lecture: Important Discussion and Decision Faced during Dementia

Friday, May 10, 10:30 – noon

Musical Instrument Museum

5001 E. Cheyenne Drive, Phoenix

Registration required: (602) 230-CARE

Brain Health Tip:

Eat a rainbow of colorful vegetables and fruits! Enjoy the deep reds of raspberries and pomegranates, the beautiful green of collards, spinach and kale, the dark purple of blueberries, and the bright orange of yams. As you enjoy these delicious foods you will be providing your body and brain with powerful antioxidants to further protect your brain!

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.