

alzheimer's association[®] desert southwest chapter

the compassion to care, the leadership to conquer

Spring 2007

The “CAREGIVING” Code Can Help You!

by David W. Coon, PhD

Family caregivers busily work every day to help loved ones with Alzheimer's and most don't recognize that taking care of themselves too is key in continuing their role. Caregiving can be mentally, emotionally and even physically taxing. The “C-A-R-E-G-I-V-I-N-G” code can help you manage stress and provide your loved one the best possible care.

Connectedness. Reach out for meaningful connections that provide informational, tangible or emotional support – family, friends and even your care recipient. Connect and re-connect, don't disconnect.

Avoid overload. When stress, the blues, or worry rises, take 5, 15, 30 minutes or more. Read a meaningful and comforting passage or spiritual reflection, listen to music, pray or meditate, or admire a sunset. Above all, be kind to yourself by acknowledging caregiving efforts and accomplishments, and saying goodbye to guilt.

Resources. Contact key community resources you have put off. Reach out to other caregivers through educational programs, helplines and support groups. When someone offers to help, provide an appropriate “to do” list or seek out their suggestions.

Educate. Remember family and friends who haven't always been around to see recent changes in your loved one. Reduce stress through a note or email providing a heads up on changes. Be brief. Describe three key issues to help prepare them for changes and formulate realistic expectations.

Game plan. Plan ahead, especially for outings and in-home get-togethers with invited guests. Keep in mind your own energy level and your loved one's limitations. Be flexible – we can't plan for everything. Look for humor and try to recount key blessings.

Invent new or transform old family traditions. Avoid the “if we can't do it the way we used then, let's not at all” trap. What can you transform or do differently to reduce overload on both your loved one and you? Identify significant others who can share the responsibilities.

Value the quality not the quantity of time. Keep it simple, less is often more. Slowing down to spend time one-on-one or in a small group with your loved one, family and friends can prove particularly rewarding. What memories, photo albums, and familiar songs can be shared?

Identify simple, pleasant events. What simple, everyday pleasant events can be maintained for your loved one, for you and for the two of you together? A daily walk in the park, time in the garden or reading a story together?

“No, thank you” is a short but indispensable phrase. A sincere “No, thank you, we can't at this time,” and suggestions on other ways to connect at a later date go a long way.

Gift giving. Sincere thank you notes and small gifts for those who help you are truly appreciated. The gift of giving often rejuvenates, but keep it simple. Finally, consider a true gift to yourself (this means no vacuum cleaners!) – a day spa massage, a gift certificate for your favorite carry out food, a new fishing pole – anything that comforts or rejuvenates.

How Can We Help?

24 Hour Helpline

Trained staff and volunteers are available to provide information, referrals and support.

Family Care Consultation

Individualized assistance by social service professionals helps persons with dementia and their families better understand, cope and plan for the future.

Support Groups

Regularly scheduled group sessions, facilitated by experienced volunteers, offer education and support to persons with dementia and/or their caregivers.

Education Programs

Programs teach families and professionals the skills necessary to provide quality care to persons with dementia, and educate everyone about the disease.

Safe Return

A national identification program assists in the location and timely return of persons with dementia who wander and become lost.

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Our Vision

A World Without Alzheimer's Disease

Our Mission

To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our Purpose

To equip, energize and ultimately empower individuals, families and communities to provide compassionate and effective dementia care and support in Arizona and southern Nevada.

Letter from the Executive Director

Dear Friends,

The personal journey of Alzheimer's disease is traveled not only by the individual with memory loss and dementia, but also by the person's family, friends, neighbors, and entire community.

I recently was privileged to spend time with families in Las Vegas and Tucson at our annual Caregiver Conferences, and was once again inspired by the courage and dedication of family caregivers. Some very special spouses, family members and friends who care for loved ones with the disease may be reading this and shaking their heads, as so many view their roles not as heroics, but simply as what is.

We often hear comments such as, "I'm only doing for my husband what he would do for me, if it were the other way around" or "My mother put up with me when I was young – it's only fair that I help her now." While the commitment we see every day is very real and truly beautiful, it still does not mean the journey is easy.

If you are a caregiver, please remember to take care of yourself, too. It is not selfish, but instead a necessity for you to be able to continue caring for your loved one. If you have friends or neighbors who are caregivers, please remember how isolating the experience can be and reach out often.

We hope that our newsletter and recently rebuilt website (www.alzdsw.org) provide helpful information to families and friends throughout Arizona and Southern Nevada. A call or e-mail to any of our Regional Offices will connect you with our programs and services to assist with your individual journey. To the family caregivers reading this, we thank you for all you do everyday.



Deborah Schaus

Deborah B. Schaus, MSW
Executive Director

Desert Southwest Regional Offices

Please feel free to contact the regional office in your area for help.

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Phoenix, AZ 85006
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928.771.9257

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Southern Arizona Region

3003 S Country Club Rd, #209
Tucson, AZ 85713
520.322.6601

West Valley Resource Center

13050 N 103rd Ave #B
Sun City, AZ 85351
623.815.2494

Southern Nevada Region

5190 S Valley View Blvd, #101
Las Vegas, NV 89118
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Planning for Future Needs with Advanced Directives

Making Descisions Now Can Save Loved Ones Pain Later

Thinking about future needs for care shortly after someone we love has received a diagnosis of Alzheimer's disease is not something a family eagerly looks forward to; however, it is an essential early step in forming the care plan for a person with memory loss.

Planning ahead is really a well-intentioned gift for the entire family, and should be seen as a positive, pro-active stance that will allow care providers and families to honor the wishes of the person with Alzheimer's when they are no longer able to communicate their wishes themselves.

What are Advanced Directives?

Advanced directives are specific, written or verbal instructions for care in case of incapacity, which adhere to the statutes of the state in which they were drawn.

Why Have Advanced Directives?

Advanced directives allow a person to pre-determine the type of care they wish to receive and to retain an active voice in decision-making about their medical care when they are too ill to do so themselves.

Advance directives also provide an opportunity for persons to appoint someone they trust to make decisions for them should they be unable to do so themselves. Both federal and state laws govern the use of advance directives and require hospitals, nursing homes, and other institutions that receive Medicare and Medicaid funds to provide written information regarding advanced directives to all patients at the time of admission.

Examples of Advanced Directives

Below are some of the most common forms of advanced Directives.

- Durable Health Care Power of Attorney
- Living Will (End of Life Care)
- Pre-Hospital Medical Directive (Do Not Resuscitate or DNR)
- Durable Mental Health Care Power of Attorney
- Letter to My Agent (Representative)
- Organ Donation
- Last Will and Testament

Plan Ahead

Creating advanced directives may be burdensome and difficult to articulate for some families. It requires thinking and discussing values, treatment options, and quality of life concerns.

However, advanced directives can provide comfort and confidence to those who must convey a person's wishes for care. It removes the burden of responsibility to guess another's intentions, and frees family members and friends of feelings of helplessness and guilt.

Discuss your wishes with family, friends and health care professionals. All states have simple forms you can fill out yourself, or seek the advice of a legal professional. Review your decisions from time to time, and remind family and friends. It's one of the best gifts you can give to those who love you.

Cameo Ball a Magical Night



Saturday January 27th, 2007, was a night of black ties and beautiful dresses at the Third Annual "This Magic Moment" Cameo Ball. Thank you to Ms. Herme Sherry, Ms. Marilyn Joyce and all the wonderful ladies of Cameo Club for putting together such a spectacular event and auction!



Ms. Herme Sherry (l), & Ms. Marilyn Joyce (r).

Well over 300 people attended this year's Ball, dancing the evening away and participating in a great live auction! Tempe Mayor Hugh Hallman, the evening's auctioneer, kept the proceedings lively, even performing a handstand to encourage bidding on a beautiful Arabian mare.

Celebrated animator Bill Keane donated three original "Family Circus" drawings to the auction. The donation included a "meet and greet" at his home and personalization for the buyers.

After the auction, guests danced the night away to the wonderful music of the Bob Messinger Band. A truly magical evening was had by all.

The pictures from the 2007 Alzheimer's "This Magic Moment" Cameo Ball are now on the website. If you would like to see them you just go to www.cameoball.com.



Keane shares a moment with two of the buyers, Jean Mathews (l), and Phyllis Turell (r).

More information on advanced directives and other long-term planning items is available at our Legal and Financial Planning education session. You can also call the Regional Office in your area for additional information.

Education Program Calendar



April 2007

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
2 Understanding Dementia and Alzheimer's Disease Chandler - 10:00 am	3	4 Partnering w/ Your Doctor Tucson - 2:00 pm	5 Planning for Placement Buckeye - 10:00 am	6	7
9	10	11 Compassionate Communication Tucson - 10:00 am	12 Meaningful Activities Las Vegas - 3:30 pm Understanding Dementia and Alzheimer's Disease Goodyear - 3:00 pm	13 Maintain Your Brain Glendale - 3:00 pm	14
16 Communication in Alzheimer's Avondale - 10:00 am	17 Community Outreach Day Mesquite Update on Research and Treatment for Alzheimer's Scottsdale - 10:30 am	18 Partnering w/ Your Doctor Las Vegas - 10:00 am Legal Issues Nogales - 1:15 pm	19	20 Making the Day Meaningful with Activities Las Vegas - 3:30	21 Maintain Your Brain Las Vegas - 10:00 am
23	24	25 Activities for Individuals Sierra Vista - 1:15 pm After Placement, Now What? Peoria - 10:00 am	26 Providing Comfort Care in Late Stage Las Vegas - 4:00 pm Activities for Individuals Tucson - 11:30 am	27 Legal and Financial Planning Sun City West - 3:30 pm	28
30 Challenging Behaviors Carefree - 10:00 am					



May 2007

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1	2 Wandering Prevention and Safe Return Tucson - 11:00 am	3	4 Community Resources for Alzheimer's Glendale - 3:00 pm	5
7	8 Update on Research and Treatment for Alzheimer's Chandler - 9:30 am Vacationing and Dementia Las Vegas - 10:00 am	9 Community Outreach Day Pahrump	10	11 Preventing Falls Goodyear - 2:00 pm	12
14 Using Hospice Avondale - 10:00 am	15 Just in Case: Making Your Emergency Plan Las Vegas - 1:00 pm	16 Compassionate Communication Nogales - 1:00 pm	17	18	19
21 Understanding Dementia and Alzheimer's Disease Mesa - 10:00 am	22 The Brain & Behavior Relationship Las Vegas - 4:00 pm	23 Legal & Financial Planning Scottsdale - 10:00 am Understanding Dementia and Alzheimer's Disease Tucson - 1:00 pm	24 Safety at Home Las Vegas - 1:00 pm	25	26
28	29 Update on Research and Treatment for Alzheimer's Carefree - 9:00 am	30 Normal Aging vs. Alzheimer's Peoria - 10:00 am Planning for Placement Tucson - 1:00 pm	31 Non Alzheimer's Disease Dementias Las Vegas - 4:00 pm		

Education Program Calendar

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
				1 Challenging Behaviors Glendale - 3:00 pm	2 Caregiver Mini-Conference Sierra Vista - 8:30 am
4 Update on Research and Treatment for Alzheimer's Avondale - 9:30 am	5 Caregiving for Dementia Class 1: AD & The Brain Las Vegas - 3:30 pm	6 Partnering w/ Your Doctor Tucson - 1:00 pm	7	8 Planning for Placement Goodyear - 2:00 pm	9 Choosing the Care That is Right for You Las Vegas - 10:00 am
11	12 Planning for Placement Chandler - 10:00 am Caregiving for Dementia Class 2: Beyond Words Las Vegas - 3:30 pm	13 Managing Caregiver Stress Tucson - 1:00 pm	14	15	16 Caregiver Mini-Conference Nogales - 8:30 am
18	19 Maintain Your Brain Buckeye - 3:30 pm Caregiving for Dementia Class 3: Positive Behavior Las Vegas - 3:30 pm	20 Challenging Behaviors Tucson - 1:00 pm	21 Caring for the Caregiver Tempe - 12:30 pm Creative Caregiving: Share Your Stories Las Vegas - 1:00 pm	22	23
25 Using Hospice Carefree - 10:00 am	26 Challenging Behaviors Scottsdale - 10:30 am Caregiving for Dementia Class 4: Meaningful Activities Las Vegas - 3:30 pm	27	28	29	30



June 2007



Caregiver Conferences Provide Valuable Information

March saw three of our regions host Caregiver Education Conferences, aimed at providing the latest information on Alzheimer's disease, giving participants *"hope for the future, skills for today."*

Each of the conferences delivered skills and techniques for caregivers, both professional and family, to use immediately. In addition, Dr. Marwan Sabbagh presented on the current state of research as well as what advances we can expect in the next few years.

Attendees learned about the latest developments in nutrition, legal and financial issues, depression, activities, and managing challenging behaviors. Dr. David Coon ended the Tucson conference with an interactive presentation about caregiver stress.

"The speakers were so helpful and informative," said one family caregiver. "I am so happy that I came. This will help me to better care for myself as well as my mother!"

If you are interested in being notified about next year's conferences, please contact the Regional Office in your area and speak with the Education coordinator.



Attendees listen to one of the presentations at the Las Vegas Caregiver Conference.

Save the Date



10th Annual Golf Classic

April 16, 2007
9:30 am registration
11:00 am shotgun start
Ancala Country Club
Scottsdale, AZ

Beauty of a Bonzer

September 15, 2007
8:00 pm
US Airways Arena
Phoenix, AZ

Memory Walk 2007

Oct 6 - Prescott, AZ
Oct 20 - Tucson, AZ
Oct 27 - Phoenix & Sun City West, AZ
TBD - Las Vegas, NV

For reservations, sponsorship and ticket information, please call either the Chapter Office or the Regional Office nearest you.

Brain Research Institute Created

The University of Arizona has been awarded \$5 million to fund a brain research institute that will tackle age-related memory loss and decline in the ability to learn, perceive and reason.

The Evelyn F. McKnight Brain Institute is being funded by the Evelyn F. McKnight Brain Research Foundation, which will donate the money over five years, with the UA raising equal matching funds.

The UA is the fourth university in the country to establish this brain institute, with other McKnight Institutes at the University of Florida, University of Alabama and the University of Miami.

The Board of Regents in June approved the institute, which will be established Nov. 1 on the UA campus. The institute director will be Carol A. Barnes, a regents professor of psychology, a research neuroscientist and a member of the Bio 5 Institute.

She has been a UA faculty member since 1990.

Barnes will use the first \$1 million of the donation to study brain function during the aging process and to develop methods that fight the effects of aging on learning abilities and the memory.

Local Groups Offer You Support

The Desert Southwest Chapter's free support groups provide a forum to share concerns, and information. Solicitations or research projects are not conducted at support group meetings.

To find a listing of the groups throughout Arizona and Southern Nevada, call our Helpline or visit our website at www.alzdsw.org

Challenging Behaviors in Dementia

by Rebekah Wilson, MSW

Challenging behavioral and psychiatric symptoms are common for individuals with Alzheimer's disease and other forms of dementia, and can be one of the most distressing effects of the disease for family and professional caregivers. Challenging behaviors, falls, and incontinence are the top three leading factors in a family's decision to place a loved one in a residential care facility. Behaviors have a significant impact on quality of life for individuals with dementia and their caregivers.

Approximately 80% of individuals with Alzheimer's disease will develop at least one behavior problem. In early stages of the disease, personality and mood changes are common, such as depression, irritability and anxiety. As the disease progresses, symptoms may include sleep disturbances, agitation, repetitive questions and actions, aggression, restlessness, inappropriate sexual behaviors, delusions and hallucinations. Individuals with dementia often experience increased agitation and other behavioral disturbances in the late afternoon and evening, which is called "sun downing."

The progressive deterioration of brain cells in Alzheimer's disease is the major cause of these behavioral and psychiatric symptoms. Confusion, the nature of caregiving, pain, acute medical problems, and environmental stressors are all factors that lead to challenging behaviors. Other causes of challenging behaviors include boredom, lack of routine, over stimulation, and the caregiver's approach.

Prevention and treatment of challenging behaviors start with good care. Prevention techniques include creating a calm environment, avoiding environmental stressors, and



Rebekah Wilson presents an education session. For a calendar of sessions, turn to page 4.

monitoring for personal comfort by checking for pain, hunger, thirst, constipation, fatigue, and infections. It is helpful to provide adequate rest periods and limit caffeine consumption to prevent or treat behavioral disturbances. Untreated pain and unmet needs are often triggers for behavioral symptoms in individuals with dementia, who may be unable to express themselves.

Behaviors are often an attempt to communicate and should be seen as a sign of discomfort. Treatment for behavioral and psychiatric symptoms should be focused on non-drug intervention strategies. The steps for non-drug management strategies include: identifying the symptom, understanding the cause behind the behavior, and adapting the caregiving environment to alleviate the behavioral disturbances.

The caregiver's approach can have a significant impact on the situation. It is important to avoid arguing, correcting, and challenging the person with dementia. Distraction, such as going for a walk, singing a song, or offering a snack, can be used to draw the person with dementia's attention away from a distressing situation. Caregivers should have a deep knowledge and understanding for the person for whom they provide care, in order to creatively tailor interventions for that individual.

How Neurologists Diagnose Alzheimer's Disease

Stephen S. Flitman, MD - www.neurozone.org - 866.864.6463

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Alzheimer's disease is a condition affecting older adults. Most patients with Alzheimer's develop symptoms in their 70s and 80s, but some are as young as 40. Frequently there is an understandable fear of "getting Alzheimer's" so individuals with memory loss tend to deny they have a problem, or try to cover up with compensations. That can work for a while, but getting the right diagnosis is important because not only is Alzheimer's treatable, many of the non-Alzheimer's diagnoses, like hypothyroidism, are too.

For the last ten years, the workup for patients with memory loss has been fairly standardized. A good history and neurological examination in the clinic are critical. Blood tests rule out other contributing factors. A brain scan is appropriate to look for structural changes in the brain. Anything else is ancillary, but may be worthwhile.

A good example would be an EEG. If a patient or family member tells me that the memory loss comes and goes, or that there are "good days and bad days," an EEG might be useful because it might show spikes and sharp waves, which are signs of epilepsy. That's a treatable condition I wouldn't want to miss.

The blood tests performed vary from clinician to clinician. At a minimum, TSH should be done to look for low thyroid and a Vitamin B12 level should be done to look for a deficiency of this important vitamin. If either is found to be abnormal, treatment by oral supplementation is straightforward.

The ApoE genotype is an optional blood test which may improve

confidence in the diagnosis. It costs over \$300 and is not covered by Medicare or some other insurance. At this time, my position is that the knowledge is not useful in the absence of symptoms like forgetfulness.

The most current practice guideline supports the use of a CT scan without iodine-based dye to look for rare structural causes in the brain which would rule out the diagnosis of Alzheimer's disease. A good example is normal pressure hydrocephalus (NPH), the finding that the water-filled spaces in the brain are expanding. This is a rare cause of memory impairment, incontinence, and gait disturbance which is reversible with surgery.

At this time, the jury is out on using PET scans for routine diagnosis. In my opinion, PET scans are not necessary (and are very expensive!) when the memory loss is well-established, but they can be helpful in a person who is having earlier age of onset (under 55) or has an unusual presentation, like progressive speech problems with generally preserved short-term memory.

The question that comes up the most is "Why bother diagnosing me? There's no cure!" Three reasons: 1) There are five approved drugs for treating Alzheimer's disease, and they can really help symptoms; 2) Maybe it isn't Alzheimer's, and it could be something reversible; and 3) We are doing clinical trials to find new treatments for patients who meet criteria, one of which is having a diagnosis.

There is no cure for Alzheimer's...yet. Only by actively identifying patients and getting them treatment will we come to the day when Alzheimer's disease is no more.

MED-SAC Members



Marwan Sabbagh - **MD, FAAN**

Geoffrey L Ahern - **MD, PhD**

Leslie Baxter - **PhD**

Charles B Bernick - **MD**

Larry Cohen - **PhD, JD**

Donald J. Connor - **PhD, PhD**

Stephen S. Flitman, **MD**

Gary Grove - **MD, FAPA**

Alfred Kaszniak - **PhD**

Louis C Kirby - **MD**

Diana B Koss - **MD**

Todd Levine - **MD**

Gary Martin - **PhD**

Robert Matthies - **MD**

Walter Nieri - **MD**

Steven Rapcsak - **MD**

Wallace Reed - **MD**

Eric Reiman - **MD**

Patricio F Reyes - **MD**

Joseph Rogers - **PhD**

Frank Ryan - **MD**

Gary Salzman - **MD**

Jiong Shi - **MD, PhD**

Upinder Singh - **MD, CMD, AGSF, FACP**

Dietrich A Stephan - **PhD**

Pierre Tariot - **MD**

Bryan Woodruff - **MD**

Disclaimer: This newsletter is being provided as a source of information courtesy of the Desert Southwest Chapter. Information contained herein is neither an implicit or explicit endorsement of treatments or care providers.

Give of Yourself – Volunteer.

Volunteer Opportunities are Available throughout Arizona and Southern Nevada

Every volunteer makes a difference as we strive to support the more than 100,000 individuals with Alzheimer's disease and their families, who live in Arizona and Southern Nevada. We offer a variety of volunteer opportunities to highlight your skills and talent. Training and support is provided for all volunteer positions. Please, contact one of the local offices for more information.

Helpline Volunteer

Lend a sympathetic ear and provide information and referrals to individuals and families affected by Alzheimer's disease. Professionals are available to help you with the more complex situations and occasional crisis.

Support Group Facilitator

Facilitate a monthly caregiver group that provides participants with a place to discuss problems, share concerns, learn caregiving skills, exchange information and lend emotional support.

Community Education

Attend community events and speak one-on-one with the people and distributing materials regarding Alzheimer's disease and the Chapter.

Memory Walk Team Leader

Organize a team of walkers for Memory Walk 2007! Encourage your friends, family and coworkers in supporting the largest fundraiser for Alzheimer's disease in Arizona and Southern Nevada.

Speaker's Bureau

Speak to community groups and organizations about Alzheimer's disease and related topics.

Clerical and Office

Answer phones, file and copy materials, with light computer and data entry work. Usually during office hours only.

Advocacy

Work with legislators and public officials to advance the causes of those affected by Alzheimer's disease.

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Phoenix, AZ
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Sun City, AZ
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