

Winter 2007

Texas Alzheimer's News



A publication of the Texas Council on Alzheimer's Disease and Related Disorders

Holidays and Alzheimer's

Alzheimer's Association

For most families, holidays are filled with opportunities for togetherness, sharing, laughter, and memories. But holidays can also be filled with stress, disappointment, and sadness.

Because of the changes he or she has experienced, the person with Alzheimer's may feel a special sense of loss during the holidays. At the same time, caregivers may feel overwhelmed maintaining holiday traditions while caring for the person with this disease. In addition, caregivers may feel

hesitant to invite family or friends over to share the holiday, for fear they will be uncomfortable with behavior changes in the family member.

If you're feeling guilty, angry, or frustrated before, during, or after holiday celebrations, it may help to know that these feelings are normal and that you're not alone. Here are some suggestions that may help to ease the burden of caregiving and make the holidays happy, memorable occasions.

ACTION STEPS

Adjust Expectations.

- Discuss holiday celebrations with relatives and close friends. Call a face-to-face meeting or arrange for a long distance

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telephone conference call to discuss major holiday celebrations. Make sure that family members understand the situation and have realistic expectations. By discussing past celebrations, you may be able to agree on how you'll handle upcoming holidays.

- Give yourself permission to do only what you can reasonably manage. No one can expect you to maintain every holiday tradition or event. If you've always invited 15-20 people to your home, consider inviting five for a simple meal. Also consider asking others to bring dishes for a potluck meal or to host the meal at their home.

- Familiarize others with your situation by writing a letter that makes these points:

"I'm writing this letter to let you know how things are going at our house. While we're looking forward to your visit, we thought it might be helpful if you understood our current situation before you arrive."

"You may notice that ____ has changed since you last saw him/her. Among the changes you may notice are _____. I've enclosed a picture so you know how ____ looks now."

"Because ____ sometimes has problems remembering and thinking clearly, his/

her behavior is a little unpredictable. Please understand that ____ may not remember who you are and may confuse you with someone else. Please don't feel offended by this. He/she appreciates your being with us and so do I. Please treat ____ as you would any person. A warm smile and a gentle touch on ____'s shoulder will be appreciated more than you know."



"I would ask that you call before you come to visit or when you're nearby so we can prepare for your arrival. Caregiving is a tough job, and I'm doing the best I can. With your help and support, we can create a holiday memory that we'll treasure."

Involve the person with Alzheimer's disease.

- Throughout all stages of preparation, involve the person in safe, manageable activities. This can help prepare the person for the holiday and give you an

opportunity to spend quality time together. You may want to begin slowly by asking the person to help you prepare food, wrap packages, hand decorations, or set the table. (Avoid using candies, artificial fruits/vegetables, or other edibles as decorations. Blinking lights may confuse the person.)

- Maintain the person's normal routine so that the holiday preparations don't become disruptive or confusing. Remember: Taking on too many tasks at one time can wear on you and the person.

- Build on past traditions and memories. Your family member may find comfort in singing old holiday songs, for example. But also experiment with new holiday traditions, such as renting seasonal videos.

Adapt gift giving.

- Encourage people to buy useful gifts for the person such as an identification bracelet (available through the Safe Return Program), comfortable, easy-to-remove clothing, audio-tapes of favorite music, videos of family members, and photo albums.

- Warn people about difficult or unsafe gifts. Advise people not to bring dangerous tools, instruments, utensils, challenging board games, complicated electronic equipment, or pets.
- Allow the person to join in giving gifts. For example, someone who once enjoyed

Craddick appoints Vogel to the Texas Council on Alzheimer's Disease and Related Disorders

~Hankins and Lewis reappointed~

Speaker Tom Craddick (R - Midland) has announced the appointment of Dr. Robert Vogel to the Texas Council on Alzheimer's Disease and Related Disorders. He also announced that he is re-appointing Mr. Grayson Hankins and Dr. Ray Lewis, both of whom were appointed to the Council by the Speaker in 2003.

"Dr. Vogel brings a wealth of experience to this Council," Speaker Craddick said. "Those who suffer from and are affected by Alzheimer's disease can be devastated by it. The work of this Council is vital, and I am pleased to appoint Dr. Vogel and to re-appoint Mr. Hankins and Dr. Lewis. They will do an excellent job for Texans."

Dr. Vogel practices internal medicine in Midland. He is the medical director for various nursing homes and home health care services and for the Rehabilitation Unit at Midland Memorial Hospital and HealthSouth Rehabilitation Hospital. Dr. Vogel is a fellow in the American College of Physicians, a member of the Midland County Medical Society, and is certified by the American Board of Internal Medicine. He attended

medical school at Baylor College of Medicine and did his residency in internal medicine at the University of Texas Medical School, both in Houston.

Mr. Grayson Hankins is the owner and president of University Pharmacy and Medical Supply, in Odessa. He was previously the owner and program administrator for Home Hospice of Odessa/Midland, LLC, where he also served as chief operating officer and marketing director. He has been a sales representative for Organon, Inc., a health care product and pharmaceutical company, and for Enclean, Inc., an industrial cleaning service for the petro-chemical industry, both based in Odessa. Mr. Hankins has a B.S. in Industrial Distribution from Texas A&M University. He is a member of the Odessa Rotary Club and the Odessa Chamber of Commerce, and he is the president of Odessa Council for Arts and Humanities.

Dr. Ray Lewis practices geriatric medical care in Fort Worth. He has served as regional chair of Vencor Ethics Committee and medical director at Vencor West Center and Vencor

Southwest Center, both in Fort Worth. In addition to serving as medical director and staff physician at various extended care facilities throughout Fort Worth, he has also been the owner and practicing physician of the East Fort Worth Medical Clinic and the clinical instructor of the Department of General and Family Practice at the University of North Texas Health Science Center. Dr. Lewis holds a D.O. and completed the Geriatric Medical and Dental Fellowship Program, both from the University of North Texas Health Science Center in Fort Worth.

cooking may enjoy baking cookies and packing them in tins or boxes. Or, you may want to buy the gift and allow the person to wrap it.

- Don't neglect your own needs. If friends or family members ask what you want for a gift, suggest a gift certificate to a restaurant, laundry, or dry cleaner, or cleaning service. If you don't receive these gifts, celebrate the holiday by giving these gifts to yourself.

- Ask for help and support. Develop a bulletin board for listing tasks and responsibilities. If someone ever asks, "What can I do to help?" you can respond with a specific idea.

Try to be flexible.

- Consider celebrating over a lunch or brunch, rather than an evening meal, to work around the evening confusion or sundowning that sometimes affects people with Alzheimer's. Also consider serving nonalcoholic drinks and keeping the room bright.

- Prepare to deal with your post-holiday letdown. You may want to arrange for in-home care so you can enjoy a movie or lunch with a friend and reduce post-holiday stress.

- Remember that holidays are opportunities to share time with the people you love. Try to make these celebrations easy on yourself and the

person with Alzheimer's disease so that you may concentrate on enjoying your time together.

Thank You to Leon Douglas

The Texas Council on Alzheimer's Disease and Related Disorders (Council) would like to express its deepest appreciation and thank you to Leon Douglas of Bertram, Texas for his service to the citizens of the State of Texas, victims of Alzheimer's disease and related disorders, their families and caregivers.

Mr. Douglas was initially appointed by Speaker James E. "Pete" Laney

on November 18, 1998 to complete the term of N. L. Douglas. He was reappointed by Speaker Laney on September 1, 1999 for a six-year term. He is being replaced by Robert Vogel, M.D. of Midland, Texas.

Leon Douglas served in many capacities while on the Council. He was a member of the Steering Committee for the Texas Consortium of Alzheimer's Disease Research Centers (Consortium). He

also served on the Search Committee to hire a Project Administrator and Epidemiologist to guide the Consortium's research efforts.

We thank Leon Douglas for committing his time and expertise to the Council and the State of Texas. His efforts and professionalism will be missed.

Texas Council On Alzheimer's Disease and Related Disorders Approves Objectives of the Texas Alzheimer's Research Consortium for 2008-2009 Biennium

Bobby D. Schmidt, M.Ed., R.S.
Program Specialist
Department of State Health Services

The Texas Council on Alzheimer's Disease and Related Disorders (Council) approved the 2008 – 2009 Biennium objectives for the Texas Alzheimer's Research Consortium (Consortium) at its August 23, 2007, meeting held in Austin, Texas. The 80th Texas Legislature appropriated \$3.9 million to the Council for the 2008-2009 Biennium. These funds are to be directed by the Council to support the activities of the Consortium. The original research funding of \$2 million was appropriated by the 79th Legislature.

The Consortium cohort of 600 subjects and associated data provide a solid foundation from which can be built an organization whose prime objectives are to conduct quality research and to be competitive with other state consortiums and research institutions for financial support from external sources. To accomplish these objectives, the following priorities were approved for funding:

- Increase the size of the Longitudinal Data Study cohort as needed to address the following research questions (including but not limited to):
 - Genetic factors associated with progression in AD and risk of developing AD
 - Extend inflammatory and cardiovascular risk factor study to produce a risk score to predict the development of AD
 - Research questions of high merit proposed but not funded in the first biennium such as the effect of insulin imbalance, depression, hormonal factors on AD
 - Pharmacogenomics – genetic factors associated with treatment response among patients with Alzheimer's disease
 - Laboratory analyses and additional data acquisition considerations
 - Perform additional laboratory analyses (genetic, biomarker, clinical laboratory) on all subjects as appropriate to address specific research questions
 - Add additional clinical and exposure information as required to extend current research questions or to answer new research questions
 - Establish a bank of tissue (DNA, blood) from each subject to extend current research questions and to serve as a valuable resource for future investigations.
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Texas Silver Alert Network

Governor's Division of Emergency Management

History

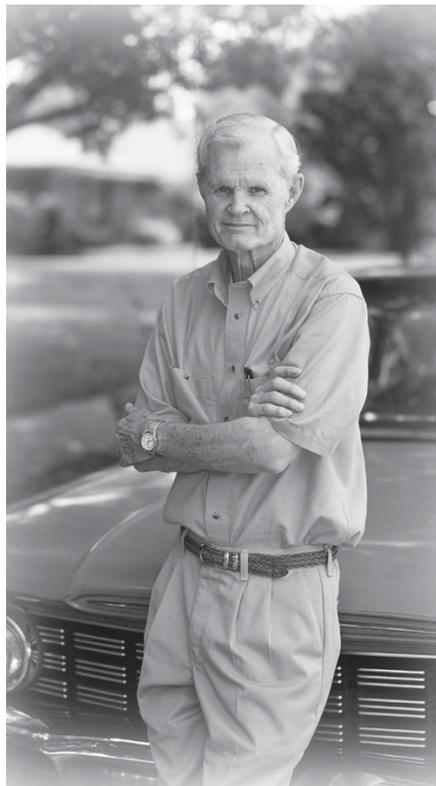
- In response to legislation enacted September 1, 2007, the Texas Department of Public Safety implemented the Silver Alert Network as a means to assist law enforcement in the recovery of missing senior citizens statewide. Silver Alerts typically resemble those alerts issued for abducted children (AMBER Alerts), using similar notification technologies (with the exception of EAS) to alert the public and media.

State Silver Alert Criteria

All five (5) criteria must be met in order to activate the Network.

- Is the missing person 65 years of age or older?
- Is the senior citizen's domicile in Texas?
- Does the senior citizen have a diagnosed impaired mental condition, and does the senior citizen's disappearance pose a credible threat to the senior citizen's health and safety? (Law enforcement shall require the family or legal guardian of the missing senior citizen to provide documentation from a medical or mental health professional of the senior citizen's condition.)
- Is the Silver Alert request within 72 hours of the senior citizen's disappearance?
- Is there sufficient

information available to disseminate to the public that could assist in locating the senior citizen? (Highway signs will be activated only if accurate vehicle information is available AND it is confirmed that the senior citizen was driving the vehicle at the time of the disappearance.)



Activation

- Once DPS has confirmed that a request for activation of the Network meets the criteria noted above, Governor's Division of Emergency Management immediately notifies the following for dissemination of

information within the advisory area:

- o Local, state and federal law enforcement agencies;
 - o Primary media outlets;
 - o Texas Department of Transportation;
 - o Texas Lottery Commission; and
 - o Independent Bankers Association of Texas.
-

Lessons Learned And Advice For Caregivers

Connie Marron Assiff

How could I ever have imagined that a disease called Alzheimer's, something I had only a vague idea of previously, and with no idea of its devastating consequences, would have such an impact on my life today? When my odyssey began, I was only 26. My husband and I decided to move my Grandmother, the mother who raised me, in with us. Her behaviors seemed odd throughout the years, but not anything that stood out to me. After all, I thought, "Wasn't it a part of growing old?"

Fast forward seven years as the young doctor tested my grandmother and confirmed the diagnosis of Alzheimer's disease. She recommended the book, *The 36 Hour Day*, by Nancy Mace and Peter Rabins. Disbelief and denial was my immediate response and eventually the guilt consumed me. I should have seen the signs. She was trying to tell me in her own way when she wasn't trying to hide it. How did I miss it? I quickly realized that the book was an invaluable reference, as I searched the index for the topic that was needed at the moment. To my amazement, I found my grandmother perfectly described on the pages. Could this really be happening? Is it possible that my grandmother, a vibrant

woman who raised such a large family and managed her own commercial business, was really fading before my eyes? Yes it was true and I had to learn all that I could and fast.

I am now 37. I am actively sharing all that I have learned



about the disease with others. My grandmother is still alive, but not able to recognize me or communicate, although she still uses real words when speaking. I guess that is some consolation. She is unable to care for herself in any way. But through this process, I came to realize that caregivers must always see the positive aspect of things, even with this disease. How am I making it these days? By volunteering my time with my local Alzheimer's Association Chapter (www.alz.org) and

empowering others on how to care for and deal with this devastating disease. Besides the book, I would recommend becoming part of a support group, enroll your loved one in the "Safe Return Program" (To register a loved one, call 1-888-572-8566) and take a course for caregivers, usually offered by the Alzheimer's Association or the Red Cross.

Educate yourself and stay informed. Seek products that are specifically made for people with Alzheimer's (www.alzstore.com). Above all, take care of yourself. If something happens to you, what will happen to your loved one? If you begin feeling depressed, overwhelmed or lonely, don't hesitate to seek assistance. Be direct and assertive when talking to friends, family or the clergy about your specific situation. The Alzheimer's Association has many resources that can help. Don't beat yourself up. We are all on this journey together and we will make mistakes, I use the mistakes I have made to help others. As long as I am learning, it is okay.

My grandmother played a major role in shaping the woman I am today and she continues to teach me life lessons through the Alzheimer's – lessons I now share with the world.

2007 Texas Conference on Alzheimer's Disease and Care Viewed As A Tremendous Success

Bobby D. Schmidt, M.Ed., R.S.
Program Specialist
Department of State Health Services

The Texas Council on Alzheimer's Disease and Related Disorders and the Texas Department of State Health Services (DSHS) would like to extend its appreciation to the Conference Planning Committee, the Bureau of Speakers, the DSHS Staff, Ms. Terri Pali, the Texas Public Health Association and the Omni Austin Hotel Downtown for their assistance in making the 2007 Texas Conference on Alzheimer's Disease and Care: Building the Future/Bridging the Gap – A Practical Approach to Alzheimer's Research - a tremendous success.

The conference was held in Austin, Texas from August 23 – 25, 2007. There were approximately 200 attendees from Texas and across the United States. The program content reflected the theme of current research being conducted and how to put that knowledge in to everyday use. The conference received excellent evaluations for the speaker's presentations, the exhibits and the conference site.

Additionally, we would like to thank the conference sponsors and exhibitors. The conference sponsors were - Forrest Pharmaceuticals, Inc.



and PamLab, L.L.C. The conference exhibitors included - Alzheimer's Prevention Foundation, AseraCare, Central Texas Regional EMS, Eisai, Inc., Harris County Area on Aging, Services for the Elderly, Inc., Texas Department of State Health

Services - Adult Health and Chronic Disease Group, Texas Department of State Health Services – Alzheimer's Disease Program, Texas Public Health Association and Texas Tech University Health Sciences Center – The Garrison Institute on Aging.

The Speaker Presentations from the 2007 Texas Conference on Alzheimer's Disease and Care may be found at <http://www.dshs.state.tx.us/alzheimers/default.shtm>.

NIA Offers New Spanish-Language Website

Accurate, up-to-date information on health issues affecting Hispanic seniors is now available online in Spanish from the National Institute on Aging (NIA), part of the National Institutes on Health. The user-friendly website has information on a wide range of health topics, including diseases such as Alzheimer's, cancer and diabetes. Helpful tips on choosing a doctor and maintaining a healthy lifestyle also are available at: <http://www.nia.nih.gov/Espanol>.

The website offers free publications in Spanish, as well as links to other health-related Spanish-language websites such as Medicare and MedlinePlus. Publications have been carefully adapted into Spanish and reviewed by Hispanic seniors.

Making health available to minority elders is a vital part of NIA's outreach to older adults. The older population in the United States is becoming more racially and ethnically diverse. According to the U.S. Census Bureau,

the number of older Hispanic adults in the United States is expected to increase from 6 percent in 2003 to 11 percent by 2030.

The NIA leads the federal government effort conducting and supporting research on the biomedical and social and behavioral aspects of aging and the problems of older people. For more information on aging research and the NIA, please visit the NIA website at: <http://www.nia.nih.gov>.

New From the National Institute On Aging

"What Happens Next?" - A booklet about being diagnosed with Alzheimer's disease or a related disorder.

A new booklet specifically for people dealing with the beginning stages of dementia is now available from the National Institute on Aging's Alzheimer's Disease Education and Referral (ADEAR) Center.

"What Happens Next?" was developed by the members

of an early-stage support group at the Northwestern University Alzheimer's Disease Center in Chicago who chose to share their thoughts and feelings because they wanted to help others like themselves. Readers will find firsthand views about diagnosis, what to expect, how to talk with others about the disease, and more. The 12-page booklet also includes a list of helpful organizations that offer written materials about dementia, information about support groups and services,

and ways to get involved in research that may help others in the future. To preview "What Happens Next?" go to: <http://www.nia.nih.gov/Alzheimers/Publications/WhatHappensNext.htm>.

Texas Council on Alzheimer's Disease and Related Disorders Current Member Roster

Appointed Members

Ronald Devere, M.D.
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Charlene Evans, R.N.
Harlingen, Texas

Debbie Hanna, Chair
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Grayson Hankins
Odessa, Texas

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For more information on Alzheimer's disease, to be placed on the newsletter mailing list, or to change your mailing address, please call 800.242.3399. There is no cost to subscribe. Newsletters are also posted on the Internet at www.dshs.state.tx.us/alzheimers.

Viewpoints expressed in this newsletter do not necessarily reflect those of the Texas Council on Alzheimer's Disease and Related Disorders.

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The 70th Legislature passed HB 1066 creating the Texas Council on Alzheimer's Disease and Related Disorders (Council). The Council was established to serve as the state's advocate for persons with Alzheimer's disease and those who care for them. The Governor, Lieutenant Governor, and Speaker of the House appoint members. The Council is composed of seventeen members. There are five public members, seven professional members, and five state agency members. The Health and Human Services Commission, Department of State Health Services, and Department of Aging and Disability Services are currently represented.



The Council has adopted as their mission to:

- Disseminate information on services and related activities to the medical and academic communities, caregivers, advocacy associations, and the general public to heighten awareness and education of Alzheimer's disease and related disorders.
- Coordinate, collaborate, and support services and activities of state agencies, associations, and other service providers,
- Encourage statewide coordinated research, and
- Recommend needed action for the benefit of persons with Alzheimer's disease and related disorders and their caregivers.



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