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Someone to Stand by You

Texas Alzheimer's News

A collaborative effort of the Alzheimer's Association Coalition of Texas and the Texas Council on Alzheimer's Disease and Related Disorders

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Risk Factors Contributing to the Development of Alzheimer's Disease

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When a family member is diagnosed with Alzheimer's disease (AD), questions often arise about the inheritability or "genetics" of the illness. In fact, the development of Alzheimer's is often due to several risk factors, not all of which are genetic or heritable. This article reviews both genetic and non-genetic risk factors associated with Alzheimer's disease.

To date, research has identified two distinct forms of Alzheimer's disease: Early Onset Familial Alzheimer's Disease (FAD) and Sporadic Alzheimer's Disease (SAD).

FAD is a rare form of the disease, usually developing before age 65 and accounting for less than 5% of all AD. Scientists believe it is caused by specific, inheritable genetic mutations. Where brain tissue biopsies or blood samples show these specific mutations, the children of the affected parent have a 50% chance of inheriting the disease.

Sporadic Alzheimer's Disease is the most common form, accounting for approximately 95% of all diagnosed cases. It is "sporadic" because no single characteristic or genetic mutation causes each of these cases. More likely, the disease develops from an interplay of several "risk factors." These include a family history, age, a history of head trauma, and possibly educational experiences. In a family with more than one case of AD, a direct genetic linkage may not be indicated and will not predict the development of the disease in the children of the affected person.

Nonetheless, family history is relevant to the development of SAD because the disease has been linked to inheriting a gene called Apolipoprotein E4 (apoE4). This gene does not directly cause SAD, but it increases one's chances of developing the disease. Some people can live a long life with this gene and never develop AD. However, apoE4 represents a "genetic susceptibility" to AD, and the disease may be "triggered" when one or more of the other risk factors mentioned above are present.

Aging increases everyone's risk of developing AD. At age 65, the risk in the general population of developing AD is about 12%. By age 80, the risk has increased to approximately 50%. It has been

hypothesized that everyone would eventually develop AD if they lived long enough (about age 130) and that the presence of risk factors simply influences how early the disease occurs.

A third risk factor is a history of head trauma that results in the loss of consciousness. Obviously, one may protect against this risk by taking precautions to avoid head injury.

A fourth, more questionable, risk factor appears to be associated with education. Those with more education are reported to be at a lower risk for developing AD. Several theories have been proposed to explain this occurrence. Maybe some highly educated people have more cognitive reserve (e.g., supply of mental processes) than those with less education. Or, highly educated people may be at equal risk for developing the disease but are more capable of masking the symptoms longer. Alternatively, people with low education may be exposed to more factors that are harmful to the brain over the course of their lives.

Finally, environmental factors are suspected of contributing to AD. Presently, researchers do not believe that exposure to an excessive amount of environmental toxins or metals (e.g., aluminum) causes AD.

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Several facilities perform genetic testing to determine the presence of the chromosomal mutations known to cause FAD. However, most research centers do not believe it is ethical to inform people of these mutations before a diagnosis of AD is made. It is also possible to test for the genetic risk factor apoE4, and this is sometimes done with patients who have dementia. Family members would not benefit from having apoE4 genotype testing because it would not tell with any certainty whether or not the disease will ever develop.

In summary, less than 5% of all cases of AD are caused by genetics alone. The majority of cases (95%) are likely caused by some combination of risk factors. If you are concerned that a family member may have symptoms of dementia, seek evaluation from qualified professionals. Comprehensive evaluation is essential to early identification, treatment, and long-term management of the condition.

Diagnosing Alzheimer's Disease

*From the
National Alzheimer's
Association*



Currently, there is no single diagnostic test that can detect if a person has Alzheimer's disease (AD). However, new diagnostic tools and criteria make it possible for a physician to make a positive clinical diagnosis of AD with an accuracy of 85-90%.

The diagnostic process generally takes more than one day and will involve the primary care physician and possibly other specialty physicians, such as a psychiatrist or neurologist. Here are the steps to diagnosing Alzheimer's disease:

- A complete medical history — includes patient's current mental

or physical conditions, prescription drug intake, and family history of health problems.

- A mental status evaluation — assesses a person's sense of time and space, and his or her ability to remember, understand, talk, and do simple calculations. The person may be asked, "What year is it?" "Who is the president of the United States?" The person may also be asked to complete mental exercises, such as writing a sentence or spelling a word backwards.
- A physical examination — includes evaluation of a person's nutritional status, blood pressure, and pulse. These tests are done to rule out other potential causes of dementia, such as cardiac, respiratory, liver, kidney, or thyroid disease, and atherosclerosis.
- A neurological examination — tests the nervous system (brain and spinal cord) for evidence of other neurological disorders, such as stroke, Parkinson's disease, brain tumor, or hydrocephalus (excess fluid in the brain), that may cause dementia-like symptoms.* In this part of the exam, physicians evaluate coordination, muscle tone and strength, eye movement, speech, and sensory abilities.
- Laboratory tests — a variety of laboratory tests may be ordered to rule out other disorders that may be causing dementia. Blood and urine tests are used to check for anemia, infections, diabetes, kidney and liver disorders, nutritional deficiencies, and abnormally high or low levels of thyroid hormone. Brain imaging techniques, such as a CT scan or MRI, may be ordered to rule out the presence of tumors, stroke, blood clots, or other factors that may be causing memory and thinking problems.
- Psychiatric, psychological, and other evaluations — designed to rule out the presence of other illnesses such as depression,

which might cause symptoms similar to those seen in AD. These evaluations test memory, reasoning, writing, vision-motor coordination, the ability to express ideas, and generally provide more in-depth information than the mental status evaluation alone.

It is important to recognize that there is no one or combination of diagnostic tests that will conclusively result in a diagnosis of AD. The tests will, however, help rule out other possible causes of the dementia-like symptoms. Once testing is completed, the diagnosing physician will review the results of the examinations, laboratory tests, and other consultations to arrive at a diagnosis. If all test results appear to be consistent with Alzheimer's disease, the clinical diagnosis is generally "probable Alzheimer's disease," or "dementia of the Alzheimer type." If the symptoms are not typical, but no other cause is found, the diagnosis may be "possible Alzheimer's disease." A definitive diagnosis of AD can be obtained upon autopsy of the brain at death.

* Dementias are a variety of syndromes involving loss of cognitive or intellectual functioning such as thinking, remembering and reasoning, so severe that it interferes with an individual's daily functioning. Changes in personality and behavior, and motor impairment are also associated with various dementias.

Legislative Updates



Community Alzheimer's Resources and Education (CARE) Program

The CARE Program was developed in response to legislation passed in 1997 mandating the Texas Department of Human Services (DHS) to

develop an Alzheimer's pilot program for the treatment of individuals with Alzheimer's disease. The program provides a continuum of care and comprehensive case management, and addresses gaps in services. In 1999, the 76th Legislature passed a rider to the Appropriations Bill to expand the CARE program. New sites include Austin, Houston, Tyler, and the Rio Grande Valley. The first four sites for the program were El Paso, Lubbock, Fort Worth and Corpus Christi.

Consortium of Alzheimer's Disease Centers

The Texas Council on Alzheimer's Disease and Related Disorders has begun plans to establish a consortium of Alzheimer's disease research centers in Texas, as directed by HB 1504 during the 76th Legislature. A steering committee of representatives from the four initial participating sites has been formed and met two times to date. As a result of their discussions, a Memorandum of Understanding (MOU) was drafted by the Office of General Counsel at the Texas Department of Health, and is currently being circulated to the institutions for their signatures. Once the MOU is signed by all sites, the steering committee will convene to develop a detailed work plan. Initial sites include Alzheimer's disease centers at Baylor College of Medicine, Texas Tech University Health Sciences Center, the University of Texas Southwestern Medical Center, and the University of North Texas Health Science Center.

Nursing Facility Reimbursement Increase

The 76th Legislature passed legislation that enabled the Texas Department of Human Services (DHS) to increase payments to nursing facilities that agree to staff at higher levels. The amount of

money available for staffing enhancements is approximately \$50 million. The new rules provide that Medicaid participating nursing facilities that agree to staff at higher levels than the statewide averages for RNs, LVNs and CNAs will receive rate enhancements. The rate enhancements are designed to reward those facilities that commit greater resources to direct care.

Senate Human Services Committee Recommendations

On June 14, 2000, the Senate Human Services Committee, chaired by Senator Judith Zaffirini, adopted a number of recommendations that could benefit persons with Alzheimer's disease. These include:

- Recommend that the legislature direct the Texas Department of Human Services (DHS) to conduct a new time study/recalculation of the Texas Index for Level of Effort (TILE), or other case-mix system to better account for varying resource needs of nursing home residents, especially those with dementia;
- Recommend that the legislature direct DHS to evaluate the effectiveness of the new Medicaid nursing facility rate methodology to incentivize increased direct care staffing and consider the addition of incentives for increased dietary and other spending to improve quality of care and quality of life for residents;
- Recommend that the legislature increase funding for nursing home reimbursements;
- Recommend that the legislature increase funding for the full range of home and community-based services, including adult day care, home health services, respite services, attendant care and other services;
- Include routine preventive dental

- services to nursing home residents as basic services under the Texas Medicaid program, contingent upon federal waiver approval; and
- Expand the Community Alzheimer's Resources and Education (CARE) program statewide by adding four additional sites.

The Alzheimer's Association Coalition of Texas is grateful to Senator Zaffirini's committee and staff for all of the work they have put into these recommendations.



Texas is one of 16 states that was awarded the Administration on Aging's (AoA's) Alzheimer's Disease Demonstration Project Grants to State Program. The grants, established by Congress in 1992, demonstrate how existing public and private resources may increase access to home and community-based services for people with Alzheimer's disease and their families. Jeanette Takamura, Assistant Secretary for Aging, Department of Health and Human Services, announced the awards on June 29 and said "these grants will offer 16 states essential new opportunities to develop innovations and more effective models of intervention that will serve persons with Alzheimer's disease and their caregivers." In Texas, the Department of Human Services (DHS) will build on its CARE program. DHS will develop a culturally and linguistically appropriate assessment process and system of care for Hispanic families who live in the San Antonio and Rio Grande Valley areas. Direct care service gaps will be addressed through development of culturally competent respite and adult day care.

Best Practices

Staffing Essential Element for Quality Care

Staffing is an essential element of a special care program for people with dementia. No matter how well designed and organized a program is, it is the staff who put "special" into a dementia specialized care program. The staff provides the continuity of care. Here are the keys to success in selecting and retaining quality staff.

Recruitment and Hiring

All direct care staff should be appropriately licensed and/or certified in the setting for which they are being hired. Staff should demonstrate dementia-capable skills and knowledge before caring for residents with dementia. Characteristics, such as, compassion, patience, flexibility, and dependability are important. Selecting good caregiving staff and adequately preparing them to care for patients with dementia will improve job satisfaction and the quality of care provided.

Orientation and Training

Provide a thorough orientation as well as ongoing education and training that adequately prepares and maintains the competency of the caregiving staff. Caring for dementia patients requires specific attributes and skills that go beyond a generic care program. It is imperative that staff understand the symptoms and behaviors associated with the disease in order to properly understand the person for whom they are caring. They must also be appropriately trained in the various components of Alzheimer's/dementia care, including activities of daily living, safety issues, and communication strategies. Examples of program content are:

- Normal aging, including cognitive, psychological and functional abilities.

- Dementia and related disorders, progression, stages and individual variability.
- Cultural values and issues of the client population.
- Interpersonal skills, effective communication methods, and team building exercises that will help staff be more effective and efficient in their caregiving role.

Retaining well-qualified caregiving staff who are committed to the care of patients with dementia and their families is not only important to maintaining quality of care, it is also cost effective. There are several areas a residential care setting should consider to maintain a quality staff:

Staffing Ratios and Patterns

Research validates that there is a positive relationship between staffing levels and the quality of care in nursing homes. To assure quality of care for persons with Alzheimer's/dementia, providers should hire and maintain sufficient numbers of staff that are well trained in dementia care. Each type of residential care setting requires a different mix of personnel based on the type of setting, amount of care needed by residents, and state/federal regulations and reimbursement guidelines. When developing staffing ratios, consider:

- The number of direct care staff necessary to provide proper care at all times – day and night.
- Potential situations that can arise and how many caregiving staff are needed to handle those situations in order to maintain a safe and secure environment.
- Staffing levels may need to be adjusted based on changing needs of patients throughout the course of the disease.

Consistency in staffing patterns is a prerequisite for creating an atmo-

sphere where trust can be built and fears reduced. Sufficient staffing is necessary to prevent burnout.

Communication

Building and maintaining the caregiving team begins with understanding team member roles and responsibilities and creating an environment where open communication is encouraged. Supervisory staff must have adequate training and skills to oversee direct care staff and to create an environment where the caregiving team can communicate freely with other team members to problem solve and share information from each of their individual perspectives. It is also important for staff to have good communication with residents and family members. Staff should be given opportunities to develop skills in working with families. This can be accomplished with regularly scheduled meetings to review care plans, informal discussions when family members are visiting, and telephone calls to give updates or share new information.

Support

People want to work in a supportive atmosphere where their unique contributions to quality care are acknowledged. Cultural values should be respected. The well being and safety of staff must be accounted for at all times. Improved working environments will generally result in reduced turnover.

Professional caregivers, like family caregivers, need sources of support to handle stress, family dynamics and other issues. Working with residents and their families can be challenging and staff members need to understand how to cope with stressful situations. Grief is common for staff who become attached to residents and families, and it is often difficult to see the disease progress in residents. Staff should be encouraged to participate in peer support groups to address these issues.

Compensation/ Opportunities

Staff should be adequately compensated for their valuable work.

Adequate wages are a vital link to staff recruitment, retention, morale, and quality care. It is also very important to provide opportunities for staff to grow both professionally and personally. Opportunities may include mentoring relationships, training or attending conferences to develop new skills, advancement to new positions, and implementing new ideas and programs. Keep in mind that respect, results, relationships and recognition motivate people.

Excerpted from "Key Elements of Dementia Care: A Presentation Kit," from the Alzheimer's Association

Caregiver Profile

The Long Good Bye

By Mary Jane Tobar

In Honor of Margaret Tobar



Care (for) = (1) to love or like (we love our mother); (2) to wish for (we wish our mother could be well); (3) to take charge of, look after, provide for (we take charge, look after and provide for our mother).

Give (ing) = (1) cause to be in trust or keeping of someone, to turn over possession or control of someone without cost or exchange.

(Alzheimer's has left our mother without control of her own life therefore it has given her the cause to give us charge and control over her life.)

Mom was diagnosed with Alzheimer's in September of 1994 at the age of 81. At the time of her diagnosis she was in the moderate stages of the disease. And so began our "long good-bye." With our oldest sister Linda, who is the main caregiver, my other sister Mary and I began to change our

mother's household (and lifestyle) a little at a time. We went from a gas stove to an electric stove and unplugged the stove after each use so she wouldn't accidentally turn the burners and/or oven on. We told our extended family and friends of her affliction so they might try to understand her actions and ours with her. We padlocked the gates to the yard so she couldn't wander away from the yard (another reason to let friends know of the disease). We began to hold her hand as we went shopping, to restaurants, or church. This gradually changed to us leading her by the hand when going places. I remember the first time I led her by the hand to church on our way to receive communion and I suddenly thought "at one time she was leading me by my hand on her way to receive communion. Our roles have reversed."

And little by little began the giving in to the use of an adult bib when eating, the use of Depends for incontinence (something I thought would come at a much later stage of her affliction). Along with this came her personal care. We bathed her, powdered her, applied lotion, dressed her, combed her hair, and did her manicures and pedicures. We served her food and cut it into bite-sized pieces when needed.

This was eventually followed by Linda taking Mom over to her house at night. Linda would pick her up every evening to sleep at her house and drop Mom back at her house every morning. During the winter months Linda slept over at Mom's house so Mom wouldn't have to go out in the cold. (Linda lives and works in the same town where Mom resides. Mary and I live and work 1 1/2 hours away. Mary and I would, and still do, take turns going home on the weekends to relieve our sister Linda).

In August of 1998 we (the family) discussed and agreed to admit Mom into a nursing home. By this time Mom did not realize she wasn't in her own house. And although it

has been two years since we admitted Mom into the nursing home, we are there every day. (Linda still being the main caregiver.) We feed her, walk her, take her to the bathroom, and dress her in her nightgown for her afternoon naps. We put her to bed at night and even say her prayers for her. Mom has lost the ability to verbally communicate with us, so we have become our mother's voice. Along with this we have developed the ability to sense when Mom doesn't feel well.

We have in a sense become one with her. And we have come "full circle." Caregiving = love = Mom.

Events

Training for Family Caregivers

The Alzheimer's Association has joined forces with the Educational Institute on Aging (EIA) and the Texas Department of Human Services (DHS) to provide state-wide training opportunities for family caregivers of persons with Alzheimer's disease. The one-day training sessions are targeted at communities where Alzheimer's caregiver training opportunities are limited. Not-for-profit nursing homes in these communities have graciously offered their facilities for the trainings. Sessions are scheduled from 10:00 a.m. to 3:00 p.m. and include lunch. The fee is \$10 and includes a copy of the Alzheimer's Association, Greater Austin Chapter's handbook "Facing the Challenge: A Practical Guide for the Alzheimer's Caregiver." Topics include: overview and stages of Alzheimer's disease; strategies for communication; activities of daily living; dealing with changes in behavior; safety; activities; and coping with caregiver stress. The trainers are Amy Matta, S.W.A., M.A.H.S. and Elizabeth Huss, R.N., B.S. of the Alzheimer's Association, Greater Austin Chapter and Debbie

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Beard, R.N., B.S.N. with the Hendrick Medical Center in Abilene. The first two programs were held in San Angelo and Lubbock, and the evaluations were excellent. Scheduled training dates and locations include: Brownwood on August 12; Waco on September 9; Wichita Falls on September 23; Texarkana on October 21; and Harlingen on November 18. To register and to arrange for care of your loved one during the training session, call the EIA at (512) 467-2242.

Council Holds Successful Conference

The Texas Council on Alzheimer's Disease and Related Disorders held a statewide Alzheimer's disease conference on April 27 and 28 in Austin. "Alzheimer's Disease in the New Millennium: Developing a Community of Care," was a great success with almost 300 participants, 27 speakers, 25 program sessions, and more than 20 exhibits. Participant feedback was excellent, with many saying it was the best

conference they had been to in years. Participants included assisted living, personal care home and long term care facility administrators, activity directors, case managers, nurses, physicians, ombudsmen, state and non-profit agency staff working with Alzheimer's disease programs, and family caregivers. The comprehensive program included the latest in research, treatment and care options, training for healthcare facility staff, a validation therapy workshop, and legal, financial, ethical, environmental, behavioral, communication and cultural diversity issues. The Council wishes to express their appreciation to speakers, sponsors, exhibitors, and conference attendees.

Texas Conference on Aging

The 2000 Texas Conference on Aging (TxCOA), formerly called The Texas Governor's Conference on Aging, is scheduled for August 21 and 22 at the Omni Hotel Southpark in Austin. The 4th annual conference is targeted to professionals and service provid-

ers working in the area of aging. In addition, a special track for physicians is planned. Continuing education credits are available for nursing facility administrators, social workers, marriage/family therapists, legal professionals, and nurses. The conference boasts a wide array of topics addressing issues related to caring for, treating, advising, supporting and celebrating our aging population. For more information call George Kelemen at 512-424-6855 or Holly Riley at 512-424-6879. The complete registration brochure is available at <http://www.tdoa.state.tx.us>.

Memory Walk

Alzheimer's Association chapters are gearing up for their annual Memory Walk events this fall. Memory Walk is the Alzheimer's Association's premier national event to increase public awareness and raise funds for Alzheimer's disease. For more information and to receive a Memory Walk registration packet, please call your local Alzheimer's Association chapter. Event dates are listed by chapter.*

About the Alzheimer's Association Coalition of Texas (AACT)

The Coalition represents the 15 chapters of the Alzheimer's Association in Texas, and their regional offices. The Alzheimer's Association is a national voluntary health organization founded in 1980 to provide information and services, including a telephone help line, family support groups, educational programs, a lending library, the Safe Return program for wanderers, in-service training, and multicultural outreach programs. The mission of the Coalition is to advocate for the improved quality of life for Texans affected by Alzheimer's disease and related disorders.



About the Texas Council on Alzheimer's Disease and Related Disorders

The Council was created by legislative mandate in 1987 to serve as the state's advocate for persons with Alzheimer's disease and those who care for them. Members are appointed by the Governor, the Lieutenant Governor, and the Speaker of the House to coordinate statewide research and education efforts, and to disseminate information on services and related activities available for persons with Alzheimer's disease to the medical and academic communities, family and professional caregivers, and the public.



**Texas Department of Health
Alzheimer's Disease Program**

1-800-242-3399

<http://www.tdh.state.tx.us/osp/alz.htm>

information and referral to community resources

Alzheimer's Association

1-800-272-3900

<http://www.alz.org>

education and support services for Alzheimer's patients, their families and caregivers

Alzheimer's Disease Education and Referral (ADEAR)

1-800-438-4380

<http://www.alzheimers.org>

information about Alzheimer's disease and related dementias

Texas Department on Aging

1-800-252-9240

<http://www.tdoa.state.tx.us>

information, referral and services for Texans 60 and older; ombudsman program

Texas Department of Human Services

1-800-458-9858

<http://www.dhs.state.tx.us/programs/index.html>

regulation of long term care facilities; licensing and certification for assisted living, adult day care, and nursing facilities; choosing a nursing home; CARE program

Elderweb

<http://www.elderweb.com/region/tx/index.html>

numerous links to information on legal, financial, medical and housing issues; community services and resources

**Alzheimer's Association Chapters
in Texas**

El Paso Chapter

4400 N. Mesa, Suite 9
El Paso, TX 79902
915-544-1799 or 877-544-1799
**September 23*

Greater Austin Chapter

P.O. Box 4829
Austin, TX 78765
512-454-5476 or 800-367-2132
**October 14*

Greater Dallas Chapter

2910 Swiss Avenue
Dallas, TX 75204
214-827-0062 or 800-515-8201
**September 23*

Greater East Texas Chapter

P.O. Box 630636
Nacogdoches, TX 75963-0636
409-569-1325 or 800-246-7888
**October 21*

Greater Texarkana Area Chapter

P.O. Box 7812
Texarkana, TX 75505-7812
903-792-6122 or 877-312-8536
**September 30*

Greater West Texas Chapter

P.O. Box 3389
Midland, TX 79702-3389
915-570-9191 or 800-682-1174
**September 23 (Midland/Odessa, San Angelo & Big Spring)*

Greater Wichita Falls Chapter

801 Burnet
Wichita Falls, TX 76301
940-767-8800
**October 7*

Houston & Southeast Texas Chapter

11251 Northwest Freeway, Suite 300
Houston, TX 77098
713-266-6400 or 800-266-8744
**September 23 (Beaumont)
October 28 (Houston & Baytown)

Northeast Texas Chapter

3613 South Broadway, Suite 401
Tyler, TX 75701-8732
903-509-8323 or 800-789-0508
**October 5*

Rio Grande Valley Chapter

902 Morgan Boulevard, Suite 2
Harlingen, TX 78550
956-440-0636 or 800-509-9590
**October 28*

South Central Texas Chapter

7400 Louis Pasteur
San Antonio, TX 78229
210-822-6449 or 800-523-2007
**October 14 (San Antonio)
October 28 (Kerrville)

South Plains Chapter

Texas Tech University Health Sciences Center
3601 4th Street, Room 3A116
Lubbock, TX 79430
806-799-4708 or 888-561-5117

Tarrant County Chapter

P.O. Box 9709
Fort Worth, TX 76147
817-336-4949 or 800-471-4422
**September 16 (Parker County)
September 23 (Ft. Worth)

The Panhandle Area Chapter

2200 West 7th Street
Amarillo, TX 79106
806-372-8693 or 800-687-8693
**October 1*

West Central Texas Chapter

P.O. Box 3344
Abilene, TX 79604-3344
915-672-2907 or 888-511-4132
**September 23*

**Memory Walk event dates*

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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 1-800-242-3399. There is no cost to subscribe. Newsletters are also posted on the Internet at <http://www.tdh.state.tx.us/osp/alz.htm>

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

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