



# 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

## Priorities and Outcomes from the 76<sup>th</sup> Texas Legislative Session

### 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 diagnosed with Alzheimer's disease. The program is operated in contiguous urban and rural counties, and provides a continuum of care and comprehensive care management. Current program sites include El Paso, Lubbock, Fort Worth and Corpus Christi.

This year the legislature appropriated approximately \$2.5 million for the biennium to fund the four current CARE sites and to expand the program to four new CARE sites in FY 2001. DHS shall also encourage positive program outcomes, identify and address gaps and services, and improve service delivery. The rider was introduced to the House Ap-

propriations Committee by Representative Kyle Janek (Houston) and was introduced to the Senate Finance Committee by Senator Robert Duncan (Lubbock).

### Consortium of Alzheimer's Disease Centers

HB 1504 directs the Texas Council on Alzheimer's Disease and Related Disorders to establish a consortium of Alzheimer's disease centers to include 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. The consortium will provide centralized, uniform services among consortium participants, including clinical services from each consortium participant's clinical center. The consortium will also establish a database that will make data available to each participant; provide a resource index to facilitate research projects; and provide

data on patient health outcomes to state agencies and researchers in Texas. The Council will establish a data coordinating center to be located at Texas Tech Health Sciences Center. The bill was introduced in the House by Representative Tony Goolsby (Dallas) and sponsored in the Senate by Senator Chris Harris (Arlington).

### Improved Protection for People with Alzheimer's Disease Who Wander

In general, a 24-hour waiting period is required before an adult is considered a "missing person" and a search can be initiated. Now, pursuant to HB 605 passed during the 76<sup>th</sup> legislative session, local law enforcement agencies are required to begin investigations of missing persons immediately if the subject is an adult reported to have chronic dementia, including Alzheimer's dementia. Local law enforce-

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ment are also required to enter the person's name into the Alzheimer's Association Safe Return program, a nationwide identification, support and registration program that assists in the safe return of individuals with Alzheimer's or a related dementia who wander or become lost. This bill was introduced in the House by Representative Sherri Greenberg (Austin) and sponsored in the Senate by Senator Kenneth Armbrister (Victoria).

### **Community Based Alternatives (CBA) Program**

The legislature appropriated \$27,500,000 in state funds for this community care program over the biennium. With this money, and an additional federal match, the average number of CBA clients served per month in FY 2000 will be 23,900 and in FY 2001 will be 26,575. By way of comparison, in FY 1999 the average number of CBA clients served per month was 22,000.

### **The Options Case Management Program**

This program provides case coordination and service arrangements for older adults who do not qualify for Medicaid. The program received the same funding that it received last session - \$800,000 in general revenue per year.

### **Adult Day Care**

The legislature appropriated an additional \$20.8 million in state funds over the biennium (with an additional federal match of approximately \$33 million over the biennium) for rate increases in community care programs under the Department of Human Services. Programs to receive rate increases were not specified.

### **Nursing Facility Reimbursement Increase**

The legislature appropriated \$27.8 million in state funds for rate increases during FY 2001. The FY 2001 year increases are contingent upon "adoption of agency rules that incentivize increased direct care staffing and direct care wages and benefits in nursing homes. . ." and assurances that "providers will comply with the new staffing reimbursement rules..."



The Coalition and the Council wish to express our sincerest thanks to all the members of the Texas Legislature who played a role in advancing these pieces of legislation and who supported the efforts of the Coalition and the Council during the 76<sup>th</sup> Texas Legislative Session.



## **Best Practices**

### **Adult Day Care**

Adult Day Care centers provide a structured setting in which people with Alzheimer's disease and other disabilities can benefit from personal counseling and other services and where they may enjoy activities such as exercise and crafts. Adult day care programs are offered in community centers, retirement homes, nursing facilities, hospitals and religious centers. Day care benefits both the caregiver and the person with Alzheimer's.

The structured activities provided in adult day care help to reduce challenging behaviors often associated with Alzheimer's by keeping clients active and involved on a daily basis. Disturbances in mood may accompany the progression of dementia. By providing a variety of therapeutic services, adult day care programs are effective in improving mood among cognitively impaired older adults.

Older adults suffering from dementia are at greater risk for health problems. Professionals at a day care center can help evaluate a person with Alzheimer's and provide the caregiver with ideas for enhancing care giving. The supervision offered by trained staff at adult day care can help prevent and properly treat a number of health problems commonly experienced by people with Alzheimer's disease.

Caregivers also benefit from adult day care programs. Centers can provide the day-to-day support to allow a caregiver to keep working or get a break from caregiving. The job of caring for someone with Alzheimer's often results in overwhelming and uncontrollable stress that can take a toll on the caregiver's emotional well-being. In many cases, the caregiver is an older adult with health problems of his or her own. As a result of the stress, caregivers often experience increased health problems as well as depression. In fact, it is not unusual for the person with Alzheimer's to outlive the caregiver.

Adult day care is a form of respite care that can alleviate the stress associated with caring for a relative. It can free up the caregiver to run necessary errands or go to a doctor's appointment. By allowing the caregiver to take care of himself or herself, both emotionally and physically, adult day care

enables the caregiver to provide better care for a person with Alzheimer's at home for a longer period of time.

The cost of care starts at approximately \$25 dollars a day. Some centers offer ser-



vices on a sliding scale, where caregivers pay according to ability or income. Medicaid covers costs for people with very low income and few assets. Medicare does not pay for adult day care.

In summary, adult day care is an effective and financially viable treatment for Alzheimer's disease. By serving as a complement to caregiving families, home-based services, and primary care, adult day care programs maintain the levels of functioning necessary to prevent excess disability and help older adults remain in the place they want to be most: home.



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Letters should be addressed to Elaine Braslow, M.Ed., Editor, Texas Department of Health, 1100 W. 49th St., Austin, TX 78756.

#### **Editorial Staff**

Kay W. Hricik, JD, MPAff, Public Policy Director, Alzheimer's Association, 512-454-5476

Elaine Braslow, M.Ed., Director, Office of Special Projects, Texas Dept. of Health, 512-458-7534.

Linda Jones, MSPH, Texas Dept. of Health, 512-458-7534.



# Alzheimer's Association Chapters in Texas

## **West Central Texas Chapter**

P.O. Box 3344  
Abilene, TX 79604-3344  
915-672-2907

## **Greater Austin Chapter**

P.O. Box 4829  
Austin, TX 78765  
512-454-5476

## **Greater Beaumont Area Chapter**

780 S. Fourth Street  
Beaumont, TX 77701  
409-833-1613

## **Coastal Bend Chapter**

4626 Weber Road, Suite E  
Corpus Christi, TX 78411  
512-854-3887

## **Greater Dallas Chapter**

2910 Swiss Avenue  
Dallas, TX 75204  
214-827-0062

## **El Paso Chapter**

4400 N. Mesa, Suite 9  
El Paso, TX 79902  
915-544-1799

## **Greater Houston Chapter**

6161 Savoy, Suite 240  
Houston, TX 77036  
713-266-6400

## **Greater West Texas Chapter**

P.O. Box 3389  
Midland, TX 79702-3389  
915-570-9191

## **The Panhandle Area Chapter**

2200 West 7th Street  
Amarillo, TX 79106  
806-372-8693

## **Tarrant County Chapter**

P.O. Box 9709  
Fort Worth, TX 76147  
817-336-4949

## **South Central Texas Chapter**

8546 Broadway, Suite 110  
San Antonio, TX 78217-6351  
210-822-6449

## **Northeast Texas Chapter**

3613 South Broadway,  
Suite 401  
Tyler, TX 75701-8732  
903-509-8323

## **South Plains Chapter**

3601 4th Street  
Suite 3a116  
Lubbock, TX 79430  
806-799-4708

## **Greater Wichita Falls Chapter**

801 Burnet  
Wichita Falls, TX 76301  
940-767-8800

## **Greater East Texas Chapter**

P.O. Box 630636  
Nacogdoches, TX 75963-0636  
409-569-1325

## **Greater Texarkana Area Chapter**

P.O. Box 7812  
Texarkana, TX 75505-7812  
903-792-6122

## **Rio Grande Valley Chapter**

1000 Camelot Drive  
Suite 6005  
Harlingen, TX 78550  
956-440-0636

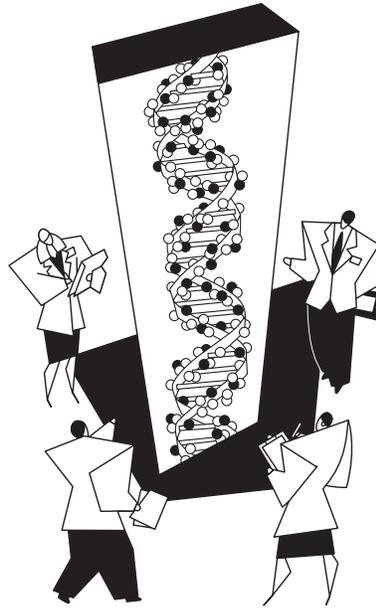
# Research Update

## TEXAS TECH DNA BANK RESEARCHERS LINK A Milder FORM OF ALZHEIMER'S DISEASE TO CHROMOSOME 3

At Texas Tech University Health Sciences Center in Lubbock, Dr. Shirley Poduslo and her research staff are searching for the cause of Alzheimer's disease. Since the disease can exist in several members of a family, there is probably a genetic basis for much of the disease. Finding the genes involved will enable the development of tests to identify people at risk of developing the disease before symptoms even start. Then it is hoped that methods of prevention can be applied.

In order to find the genes involved in the development of Alzheimer's disease, the DNA Bank - a collection of DNA samples from Alzheimer's patients and their family members who live around Texas, was established at Texas Tech. The DNA Bank includes samples from the patient and his or her spouse, the patient's siblings and children and their respective spouses, and even the grandchildren. The more people who enroll in the DNA Bank, the better the chances are of finding the cause of the disease.

Here's an example of how it works. A patient with the clinical signs of



Alzheimer's disease, including progressively worse memory loss, enrolled into the DNA Bank. The patient had 3 siblings who were similarly affected. The mother also had several siblings with severe memory problems. The patient lived with the disease for 13 years. After death, an autopsy was performed. The characteristic signs of Alzheimer's in a brain at autopsy are the loss of neurons and presence of plaques and tangles. The patient's brain in this study had plaques only. There were no tangles. The researchers were puzzled. They thought that maybe this patient had a dementia other than Alzheimer's disease. There was a report by a group of

California researchers suggesting that 30% of elderly Alzheimer's patients may have plaques but no tangles at autopsy. These researchers concluded that the patients without the tangles also had Alzheimer's, but a less severe form than if they had both plaques and tangles.

The family enrolled in the DNA Bank fits into this category of Alzheimer's disease in which plaques but not tangles are found in the brain at autopsy. At Texas Tech the researchers were able to show that this form of Alzheimer's disease is linked with markers on chromosome 3. The researchers are now looking for the gene in chromosome 3 that may be mutated in this milder form of the disease. Identifying markers and genes linked with the disease will assist in clinically subclassifying patients according to their presenting symptoms and in identifying potential responses to new drugs coming on the market. This exciting research is made possible not only by the dedicated efforts of Dr. Poduslo and her staff, but also by the patients and their families who have enrolled in the DNA Bank.

Thanks to all!





# Alzheimer's Disease in the New Millennium: Developing a Community of Care

If you are a physician, legislator, ombudsman, healthcare facility administrator, activity director, nurse, case manager, home health aide, or family caregiver,

**SAVE THESE DATES**

**April 27 and 28, 2000**

**Red Lion Hotel, Austin**

The Texas Council on Alzheimer's Disease and Related Disorders and the Texas Department of Health present a comprehensive, cutting edge conference!

## **Topics:**

- ☛ advances in treatment and care
- ☛ latest in genetic research
- ☛ legal, financial, ethical, environmental, behavioral, and cultural diversity issues
- ☛ special training for healthcare facility staff
- ☛ validation therapy workshop
- ☛ care options, quality indicators, and community resources

## **Speakers:**

Marcelle Morrison-Bogorad, Ph.D., National Institute on Aging

Rachelle Doody, M.D., Ph.D., Baylor College of Medicine

Shirley Poduslo, Ph.D., Texas Tech University Health Sciences Center

Myron Weiner, M.D., UT Southwestern Medical Center

Naomi Feil, M.S.W., Validation Training Institute

Liz Carpenter, Author and Former Press Secretary to Lady Bird Johnson

And numerous other experts in the treatment and care of individuals with Alzheimer's disease

**Continuing education units for multiple disciplines will be available.**

Call 1-800-242-3399 in February to receive a conference brochure including complete program, session descriptions, and registration information.

For now, save these dates: April 27 and 28, 2000!

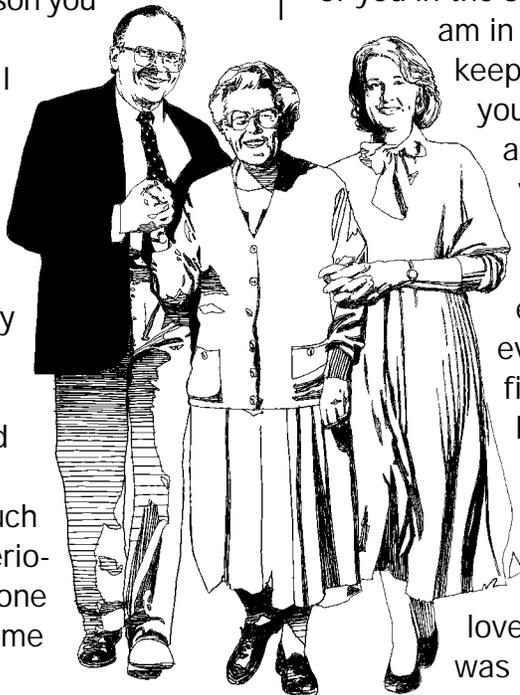
# Caregiver Profile

## Coping With a Loss

by Frances Plotsky

And it is a loss! The person you've been intimate with, have children with, have loved for many years is not the same person you married.

When I first attended the Shoal Creek Hospital Support Group, I really didn't like what I was hearing. I did not want to learn how much patients deteriorated. Then one day a lady came from Taylor bemoaning her life taking care of her husband with Alzheimer's disease. She was almost in tears telling us that all her friends had deserted her, never visiting, never inviting them out, and never calling. I suddenly realized how lucky I was - my friends have been wonderful. "I've made a pot roast for dinner tonight and I know that it's one of your favorites." "We're going to Luby's for supper, come join us." And it



goes on! I have 3 daughters - all very busy. One lives in Ft. Worth and has 3 teenage sons, plus teaches preschool; one lives in Houston and is the general manager of her husband's office; and the oldest lives in Austin. She is a nurse supervisor, married, and busy. They all come at first call if I need them, but I don't see them as often as I'd like.

So, my advice to those of you in the same position I am in - stay active, keep in touch with your friends, keep active in your various activities - bridge, mah jongg, exercise, whatever. When Mort first went into a home 5 years ago, I had company for dinner every two weeks. I love to cook and it was therapeutic to see my friends. I

can't do it as often now because of a hip that just won't cooperate. I belong to our Sisterhood at my temple and go to religious services as frequently as possible. I promised myself 5 years ago to take care of my health. I have one good meal each day, mostly what I cook.

It is a drag this disease - going on and on. Like Nancy Reagan said, "It's a long goodbye." I keep re-

minding myself of the good 50 years out of the 57 we had in our marriage. I still leave Gracy Woods many a day with tears in my eyes - hating to leave the hand that is holding mine so tightly. I remember a loving family, civic work that we did, and happy times. That helps.

Yes, I am lonely. I miss him terribly, but I feel lucky. I loved and was loved in return.



## Caregiver Tip

When people offer to help, don't be shy about accepting the offer and suggesting specific things they can do.

## Caregiver Resources

### Alzheimer's Association

1-800-272-3900

<http://www.alz.org>

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

1-800-242-3399

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

### National Family Caregiver Association

1-800-896-3650

<http://www.nfcacares.org>



## **The Alzheimer's Association Coalition of Texas(AACT)**

is a coalition of the 17 chapters of the Alzheimer's Association - a voluntary national health organization founded in 1980 to provide services including a telephone help line, family support groups, educational programs, a lending library, the Safe Return program for wanderers, dissemination of information, 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.

## **The Texas Council on Alzheimer's Disease and Related Disorders**

was created by legislative mandate in 1988 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, as well as, 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.