

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

2006
Biennial
Report

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Chair
Texas Council on Alzheimer's Disease
and Related Disorders

M

essage from the Chairman

The National Alzheimer's Association estimates that at the current rate, 552,000 Texans will have AD by 2025, and 14 million Americans will have AD by 2050.

On behalf of the Texas Council on Alzheimer's Disease and Related Disorders, I am pleased to present our 2006 biennial report of activities and recommendations. Over the past two years, the Alzheimer's Disease and Related Disorders Program has had many successes, and a few challenges. This report will detail the highlights of FY 2005 and FY 2006.

Alzheimer's Disease (AD) is an age-related, degenerative brain disorder that manifests itself in problems with memory, thinking, and behavior severe enough to interfere with everyday life. Over time, as cognitive and functional abilities decline, individuals with AD are rendered dependent on others for all of their care. Bodily functions eventually shut down and they succumb to death.

There is growing concern among the public about AD, with very good reason. The likelihood of developing AD increases with age. At present, there are approximately 4 million Americans and 280,000 Texans who have been diagnosed with AD. With the first of the 76 million baby boomers reaching age 65 in 2011, AD and other age-related diseases will increase dramatically. The National Alzheimer's Association estimates that at the current rate 552,000 Texans will have AD by 2025, and 14 million Americans will have AD by 2050 in the absence of prevention or cure.

The imminent surge in the number of people with AD poses particular challenges and opportunities to Alzheimer's professionals and advocates. For example:

- Clinicians are challenged to identify and treat individuals with AD at the earliest stages of the disease to delay its progression. Aside from prevention and cure, this strategy offers the best opportunity to contain healthcare costs and help persons with AD remain independent for longer periods of time.



- Researchers are challenged to work towards Alzheimer's prevention and cure, but also to find ways to delay the onset of symptoms until later in the life span. People may live with a diagnosis of AD longer but with less disability and more independence.
- AD stakeholders must take every opportunity to advocate for programs and services to support individuals with AD and family caregivers. Continued funding of home and community-based services will sustain the family caregiving system, and contain costs by keeping individuals at home. Increasing reimbursement rates to long-term care providers to elevate staffing levels, improve wages and benefits, and add dementia training will assure the availability and quality of long-term care.

AD is clearly a growing national and international health problem. Investing in research, programs that support individuals with AD and their caregivers, and improving the quality of long-term care is critical as we work toward ending this devastating disease.

Debbie Hanna
Chair

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Texas Council on Alzheimer's Disease and Related Disorders

20 Years of Progress

The Texas Legislature created the Texas Council on Alzheimer's Disease and Related Disorders (Council) in 1987. To commemorate this milestone, this document includes a timeline that highlights some of the many accomplishments with regards to Alzheimer's Disease education, research and funding in Texas and nationally.

The Governor, Lieutenant Governor and Speaker of the House appoint the Council members. Since its inception, the Council has partnered with private organizations and academic institutions to promote professional and patient education and public awareness. The Council also advises the Legislature on laws needed to further education and research for people with Alzheimer's Disease and Related Disorders.

A complete list of the Council members is included in Appendix A.

1987

- The U.S. Office of Technology Assessment publishes the first major government report on Alzheimer's disease, *Losing a Million Minds: confronting the tragedy of Alzheimer's disease and other dementias*.
- The gene responsible for amyloid precursor protein (APP) is sequenced. APP is broken down to form the beta-amyloid protein of Alzheimer's plaques. This research is partly funded by the Alzheimer's Association.
- The 70th Texas Legislature passes HB 1066, creating the Council and charging it with developing needed action for the benefit of victims of Alzheimer's disease and related disorders and their caregivers, focusing on clinical research.

1988

- National Respite Care Demonstration Program, supported by funding from the Robert Wood Johnson Foundation, begins at 19 national sites.
- The book *Understanding Alzheimer's Disease, What It Is, How to Cope With It and Future Directions*. Written by Miriam Aronson, this is one of the first consumer books on the disease.
- Action Senior Companion Program starts in nine communities.

1989

- First Public Policy Forum in Washington, D.C., April 2-5.
- For the first time, congress appropriates over \$100 million (\$129) for Alzheimer medical research.
- First Alzheimer's Association Memory Walk is held.
- JAMA: the Journal of the American Medical Association publishes a research paper that reports Alzheimer's disease is more

prevalent than previously thought. The revised figures state that approximately four million people are affected.

1990

- Zenith Fellows Program, an honorary society of individuals and organizations who commit \$1,000,000 is established.
- *Alzheimer's Orientation Kit and the Caregiver Kit*, containing both video and print products, are released.

1991

- Federal government funds more than \$200 million for Alzheimer's research (\$229 million), marking the first time funding exceeds \$200 million.
- Alzheimer's disease is the cover story in an issue of *U.S. News & World Report*.
- Tau protein is identified as the main component of neurofibrillary tangles, one of the characteristics of Alzheimer's disease.
- HBO special entitled "Losing It All: The reality of Alzheimer's disease." This special depicts the emotional, financial and physical demands of care giving.
- U.S. Food and Drug Administration agree to put Alzheimer drug testing into the accelerated track.

1992

- The Alzheimer's Association achieves a presence in all 50 states.
- First National Alzheimer's Disease Education Conference for care providers takes place in Chicago on July 12-15.
- *Guidelines for Dignity*, standards for Alzheimer specific care is released.
- A culturally appropriate video kit, *Unidos en la lucha*, is produced for the Hispanic/Latino community.

1993

- First nationwide Memory Walk is held.
- Safe Return program is launched to assist in the identification and safe, timely return of individuals with Alzheimer's disease who wander and become lost.
- "Is It Alzheimer's? Warning Signs You Should Know" (10 Warning Signs) awareness campaign is launched.
- Tacrine (Cognex) is approved by the U.S. Food and Drug Administration as the first drug for the treatment of Alzheimer's disease.
- The gene responsible for apolipoprotein E is sequenced. People with certain versions of the gene (E4) have a higher risk for Alzheimer's disease.

1994

- Federal government approves over \$300 million for Alzheimer's research (\$302 million).
- In November, former President Ronald Reagan announces that he has been diagnosed with Alzheimer's disease.
- Alzheimer Disease International (ADI) announces the first World Alzheimer Day to take place on Sept. 21.

1995

- The Ronald and Nancy Reagan Research Institute is established.
- First integrated education and program plan is produced.
- Transgenic mouse models are developed for Alzheimer disease, improving researchers' ability to study the disease.

1996

- Completed caregiver survey quantifies the hardships caregivers face in caring for those with Alzheimer's.
- Donepezil hydrochloride (Aricept) is the second drug approved by the U.S. Food and Drug Administration specifically to treat Alzheimer's disease.

1997

- A toll-free number is established for Safe return telephone enrollment and information, and master level clinicians begin to answer the Safe Return Incident line for wandering incidents.
- Key Elements of Dementia Care document is finalized and distributed.
- Statewide coalition building began with Attorney Generals in several states.

1998

- Alzheimer's Disease Prevention Initiative results in a \$50 million increase in federal funding for Alzheimer research, bringing total federal commitment to Alzheimer research to over \$400 million.
- A new report is issued calculating, for the first time, the cost of Alzheimer's disease to American business - \$33.26 billion a year.
- The Assisted Living Quality Coalition (a consumer-industry effort) releases a proposal for an Assisted Living Quality Initiative to define minimum standards and build a structure to promote quality assisted living.
- A Medicare Advocacy Project is established with the American Bar Association's Commission on the Legal Problems of the Elderly to improve Medicare coverage of care and treatment for the beneficiaries with dementia.
- A Reagan Institute work group publishes a "Consensus Report on Molecular and Biochemical Markers of Alzheimer's Disease" in *Neurobiology of Aging*

1999

- The National Institute on Aging Memory Impairment Study – a test of the usefulness of two drugs to slow or stop the progression of mild cognitive impairment to Alzheimer's disease – a meaningful step toward preventing the disease.
- Scientists develop a vaccine that, when used on mice, appears to ward off and even reduce the plaque deposits commonly found in the brains of people with Alzheimer's.
- A study is released, "Economic Value of Informal Caregiving in the U.S.", that indicates \$196 billion a year is contributed to the U.S. health care system by an invisible health care sector – families and friends who provide care at home for the chronically ill.

Caregiving for people with Alzheimer's is estimated to make up one-third of the total informal caregiving value.

- The 76th Texas Legislature passes HB 1504 establishing a consortium of Alzheimer's disease research centers in Texas.
- Texas Newsletter Established – Texas Alzheimer's News

2000

- World Alzheimer's Congress 2000 brings together 5,000 of the world's leading Alzheimer's researchers, health care professionals, and caregivers.
- During the World Alzheimer's Congress 2000, President Clinton announces that he is earmarking \$50 million in additional funds for Alzheimer's research at the National Institutes of Health.
- Time and Newsweek magazines run cover stories on Alzheimer's disease.
- Rivastigmine (Exelon) is the third drug approved by the U.S. Food and Drug Administration specifically to treat symptoms of Alzheimer's disease.
- Texas Alzheimer's Conference 2000 – Alzheimer's Care: The New Millennium
- Texas Alzheimer's 1- 800 Hotline Established – "Help is a Phone Call Away"

2001

- Federal research funding reaches \$520 million.
- Galantamine hydrobromide (Reminyl) is the fourth drug approved by the U.S. Food and Drug Administration to specifically treat symptoms of Alzheimer's disease.
- In response to pressure from the Medicare Advocacy Project, a joint initiative of the Alzheimer's Association and the American Bar Association's Commission on Legal Problems of the Elderly, Medicare bans discriminatory denial of claims for beneficiaries with dementia.
- Texas Alzheimer's Conference 2001 – Alzheimer's Care: Making a Difference in Everyday Life

2002

- A new edition of *Alzheimer's Disease: The Costs to U.S. Businesses* is released. It indicates an increase in costs to more than \$61 billion, nearly twice the amount calculated four years ago.
- The Research Roundtable is founded. This partnership unites scientists from pharmaceutical companies, universities and regulatory agencies in a collegial effort to surmount common barriers to progress in Alzheimer's research.
- President George W. Bush proclaims November National Alzheimer's Disease Awareness Month, 20 years after President Reagan's initial proclamation.

2003

- Research published in the *Archives of Neurology* estimates 4.5 million people in the United States have Alzheimer's disease and

projects a range from 11.2 to 16 million by the year 2050.

- Diversity Toolbox is launched on the Web site, alz.org, with culturally sensitive information for Black/African American, Hispanic/Latino, Korean and Chinese communities. The toolbox is intended for health care professionals to use in improving outreach efforts.
- Partnering With Your Doctor is launched to empower consumers to obtain better health care and have more effective doctor visits.
- Memantine (Namenda) wins approval by the U.S. Food and Drug Administration in October 2003 as the first drug approved for treatment of symptoms of moderate to severe Alzheimer's.

2004

- The Alzheimer's Association launches a national campaign to change the way Americans think about Alzheimer's disease. *Maintain Your Brain* kicks off with a report on baby boomers' awareness of Alzheimer's and their perceptions about the future of the disease. Later a workshop is launched on *Maintain Your Brain: How to live a brain healthy lifestyle*.
- The world mourns the loss of President Ronald Reagan 10 years after announcing his Alzheimer diagnosis.
- Congress appropriates \$1.6 million for the Centers for Disease Control and Prevention (CDC) to educate health professionals and the public on lifestyle strategies to reduce the risk of Alzheimer's disease. This appropriation marks the first time CDC has received funding for an Alzheimer program.
- Medicare starts paying for specialized brain scans in some patients to help determine if they have Alzheimer's disease.
- The new Alzheimer drug, memantine (Namenda) is launched in January. This is the first in a new class of symptomatic drugs and the first approved for individuals in moderate to severe stages of Alzheimer's.

2005

- The 79th Texas Legislature appropriates \$2 million for the Texas Consortium of Alzheimer's Disease Research Centers (Consortium).
- The Council executes Memorandum of Agreements with the Consortium member institutions.
- Texas Alzheimer's Conference 2005 – Alzheimer's Care: Innovation and Practice for Everyday Life

2006

- The Council approves a contract with a Project Coordinator to coordinate Consortium activities.
- The Council approves the recommendation for an Alzheimer Disease Data System and a Research Epidemiologist.
- The Council approves the Consortium to conduct a Longitudinal Study and two research projects centered on genetic and biomarker studies.

Alzheimer's Disease – An Urgent National Health and Research Priority

Significance of Alzheimer's Disease

Alzheimer's Disease (AD) is a progressive and, at present, irreversible brain disorder that is characterized by a steady decline in cognitive, behavioral and physical abilities severe enough to interfere with everyday life and necessitate full time care. The hallmark symptoms of memory loss, disorientation and diminished thinking ability follow a downward spiral to include problems with verbal expression, lessening analytical ability, frustration, irritability and agitation. As the disease progresses, physical manifestations include loss of strength and balance, inability to perform simple tasks and physical activities, and diminished bladder and bowel control. As more and more of the brain is affected, areas that control basic life functions like swallowing and breathing, become irreversibly damaged, eventually resulting in death. The course of the disease and the rate of decline will vary from person to person, ranging from an average of eight years to more than twenty years from the onset of symptoms.

An estimated four million Americans currently have AD. With the aging of the U.S. population, the number of those with AD is increasing rapidly and is projected to exceed 14 million by 2050. An estimated 280,000 Texans have AD with a projected 552,000 expected by 2025.

Although AD is not a normal part of aging, it is considered an age-related disorder, affecting up to 10% of people at age 65 and increasing to 50% at age 85 and older, although some people have been diagnosed with the disease as young as their 30's or 40's. These prevalence rates take on increasing significance when we consider that the U.S. population older than 65 is expected to increase from its present 13% to 18% by 2025. With the first of the 76 million baby boomers reaching 65 in 2011, AD and other age-related diseases will rank among the leading causes of morbidity and mortality. Alzheimer's is already the 7th leading cause of death and the third leading cause of disability in Texas. This has significant economic and human ramifications for an already burdened society.



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Direct and indirect costs for medical and long-term care, home care, and loss of productivity for caregivers are currently estimated at **\$100 billion per year** in the U.S.

Direct and indirect costs for medical and long-term care, home care, and loss of productivity for caregivers are currently estimated at \$100 billion per year in the U.S. This figure may be conservative when one considers the results of a recent report commissioned by the National Alzheimer's Association that looked specifically at AD related expenditures by American Businesses.¹ The report focused on two areas: (1) the cost to businesses for family caregivers, and (2) the business share of health and long-term care expenditures for people with AD. Caregiving costs include absenteeism, productivity losses, and replacement costs of workers who care for loved ones with AD, and are estimated to be \$36.5 billion per year. In addition to those expenses, the business share of healthcare for people with AD, and taxes dedicated to federal funding of AD research add another \$24.6 billion each year. The combined total equals \$61.1 billion annually. The study also compares current figures with a similar study published in 1998, when business expenditures were calculated at \$33 billion for the year.² Costs have almost doubled in this timeframe. Further, these cost projections are based on the current estimate of Americans who have AD and will rise exponentially with an accelerated growth in the aging population.

The costs to American businesses are staggering, but represent just a portion of total healthcare and long-term care expenditures for AD. They do not, for example, reflect the billions of dollars spent by state and federal governments on Medicare and Medicaid, nor the out-of-pocket expenses incurred by family caregivers. Much of the care provided to individuals with AD is considered custodial care and insurance policies typically do not cover it. What economic value do we assign to the efforts of the millions of informal caregivers who provide long-term care at no charge to their family members?

The human toll on AD patients and the informal network of family and friends in charge of their care is inestimable. Of the 4 million Americans with AD, approximately 70% live at home, receiving most of their care from family members. While each caregiving experience presents its own special circumstances, a recent national survey conducted by the National Alliance for Caregiving and the American Association of Retired People (AARP) pointed out the unique challenges faced by those providing care for individuals with AD.³ Typically, AD caregivers provide more help with activities of daily living, are more likely to report physical and emotional stress, and experience considerable financial strain.

AD exacts an enormous toll on the healthcare system, American business, families, and individuals. It is a serious problem affecting many aspects of our society. Until we can prevent and/or cure it, the impact of AD will continue to intensify.

¹ Koppel, Ross, Alzheimer's Disease: The Cost to U.S. Businesses in 2002, Alzheimer's Association; June 2002.

² Koppel, Ross, Alzheimer's Cost to U.S. Business, Alzheimer's Association; 1998.

³ Family Caregiving in the U.S. Findings from a National Survey, National Alliance for Caregiving and AARP; June 1997

Progress Through Research and Advocacy

Much has been learned about the pathophysiologic basis of AD, resulting in a more clearly recognizable clinical pattern. The findings have helped to clarify differences between normal age related memory changes, Mild Cognitive Impairment (MCI), AD and other dementias. MCI involves memory impairments, but with preservation of daily functional ability. AD causes fundamental changes in multiple realms of cognition and behavior, even early in its course. It is this loss of function that defines the transition into AD. Better understanding of the course and presentation of the disease has led to earlier detection and more definitive diagnoses.

Scientists have also identified genetic and biological changes that occur with AD, allowing them to pinpoint possible targets for treatment. Advances in pharmacologic treatment may stabilize and delay the progression of AD symptoms. This delay in progression helps contain costs associated with medical and long-term care, eases caregiver burden, and allows the individual with AD the opportunity to participate more fully in life and postpone dependency.

The death of President Ronald Reagan and the media coverage of his life and illness, coupled with strong advocacy from the Alzheimer's Association and other stakeholders has put AD in the public eye. Increased public awareness and the demand for elder care services in general has led to a proposed increase in the national research appropriation by the Senate Appropriations Committee, as well as funding for family caregiving programs and services.

Public Health Challenge and Research Priority

AD poses a particular public health challenge, and research priority because of its detrimental effects on the individual, families, and the economic system. Each of these effects will be amplified in the wake of a burgeoning aging population. Though strides have been made in its diagnosis and with symptomatic and disease-modifying treatments, there is a long way to go toward prevention and eventual cure.

Though much progress has been made in arriving at a differential diagnosis of AD, there remain significant barriers to early detection. Disease-specific areas of cognitive and functional decline render patients less likely to seek care on their own and reduce their effectiveness as



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reporters of their overall ability. Many individuals with AD do not recognize that they are impaired. This can range from mild denial of impairment to frank unawareness of the disease. In earlier stages of the disease, individuals often mask their symptoms by attributing them to old age and by ordering their environment to provide cues to remember people and events. It is often not until the individual's thinking and behavioral difficulties intensify that family members and friends are alerted to a problem and seek medical help. For those living alone, identification of a problem may be further delayed.

The importance of early detection cannot be over emphasized. The earlier the diagnosis, the more likely symptoms will respond to treatment. Additionally, many conditions with dementia-like symptoms are reversible. Early identification and aggressive treatment of AD and other dementias offer the greatest opportunity for cost decreases through timely reduction in the rate of disease progression. Other benefits to early detection include safety of the individual with AD, opportunities for caregiver education, and advanced planning of personal and legal issues while the affected person can still participate.

Increased support for individuals with AD and their caregivers is paramount. Stakeholders must continue to advocate for community and home-based care and support for caregivers. Costs for formal care for patients in treatment facilities are four times higher than for patients treated in the community.⁴ With earlier detection and improved treatment strategies, disease progression and probable institutionalization can be delayed. Continued advocacy for case management and caregiver support programs is crucial because these programs afford caregivers the assistance they need to help care for their loved ones at home. The advocacy for these services and identification of new sources of these services becomes more important in light of the recent (2003) loss of the Community Alzheimer's Resources and Education Program (CARE) in the state of Texas.

Ongoing research efforts to find the causes/risk factors, to delay onset, and to prevent and cure AD are imperative. As methodologies are refined, scientists and clinicians will be able to investigate and understand the very earliest pathological and clinical signs of AD – perhaps 10 to 20 years before a clinical diagnosis is made. Drug development to block progression of symptoms and eventually prevent AD is critical to decrease morbidity and mortality, contain healthcare costs, and protect individuals and families.

⁴ Leon, J., Cheng, C.K., Neumann, P.J., Alzheimer's Disease Care: Costs and Potential Savings, Health Aff, 1998; 17: 206-216

Texas Council on Alzheimer's Disease and Related Disorders

Background and Overview

Realizing the imminent problem of age-related neurodegenerative diseases, the 70th Texas Legislature passed House Bill 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 (AD) and those who care for them. Specifically, the Council serves to increase awareness of AD and its impact on Texans; act as a strategic partner and coordinating body for statewide education and research activities related to AD; and support policies and programs that benefit people with AD and their caregivers.

The Council is composed of seventeen members who are appointed by the Governor, the Lieutenant Governor, and the Speaker of the House. There are five public members, seven professional members, and five state agency members (agencies represented changed after the 2004 reorganization of health and human service agencies). 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.

Council Members

Ronald Devere, M.D.

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Charlene Evans, RN

Debbie Hanna, Chair

Grayson Hankins

The Honorable Clint Hackney

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Ray Lewis, DO

Audrey Deckinga

Sam Shore

Jennifer Smith, R.D.H., M.S.

Winnie Rutledge

Michael Wilson, Ph.D.

Awareness



E D U C A T I O N

Council Activities

Awareness and Education

Toll Free Hotline

Since its inception, the Council has worked to develop a growing awareness of the tremendous impact AD and related disorders have on individuals, families and society. Ongoing awareness and education activities aimed at disseminating information about programs and services have been its cornerstone. Texas Department of State Health Services (DSHS) staff who support the Council and their work, maintain a toll-free information line that receives over two hundred calls each month answering questions about all aspects of AD and caregiver services. Over one hundred comprehensive information packets are disseminated to the public each month and numerous referrals to local community services are made. Staff research and find answers to difficult questions, and follow-up with individuals to make sure they have been helped when referrals are made.

Website

DSHS staff also maintain a website, which contains general information about AD – warning signs, diagnosis, and treatment – as well as legal and financial issues, options for care, lists of licensed nursing facilities and assisted living facilities certified for the care of individuals with AD and helpful toll-free phone numbers and internet links. The website is visited by more than 600 consumers each month. It may be accessed at www.dshs.state.tx.us/alzheimers/alz.htm.

Biannual Newsletter

The Council, in collaboration with the Alzheimer's Association Coalition of Texas, produces the *Texas Alzheimer's News*, a biannual newsletter, which is mailed to 4,000 nursing facilities, assisted living facilities, adult day care centers, universities, physicians, ombudsmen and family caregivers. Recent editions of the newsletter can also be accessed from the Alzheimer's website. *Texas Alzheimer's News* features research and legislative updates, information on programs and services, best practices in the diagnosis, treatment, and care of individuals with AD, information on upcoming events and caregiver resources and services.

Biennial Conference

The Council plans and conducts a biennial conference for healthcare providers, faculty, state and local public health workers, staff from nursing facilities, assisted living facilities, adult day cares and home health services, social workers, case managers, and family caregivers.

The Council plans to host the Alzheimer's Conference in June of 2007. Conference planning began in May of 2006. The conference will be held in Austin, and the theme will be "2007 Alzheimer's Care: Bridging the Gap Through Research".

Collaboration With and Support of Programs and Services

The Council, in its efforts to coordinate, collaborate and support Alzheimer's related services and programs throughout the state, has formed solid partnerships with many service organizations, including the Alzheimer's Association, the Health and Human Services Commission (HHSC), and the Texas Department on Aging and Disability Services (DADS). Council members and DSHS staff serve on advisory and planning committees, guiding the direction and promotion of programs specifically designed to assist individuals with AD and their caregivers. The Texas Family Caregiver Support Program is an example of Council collaboration and support.

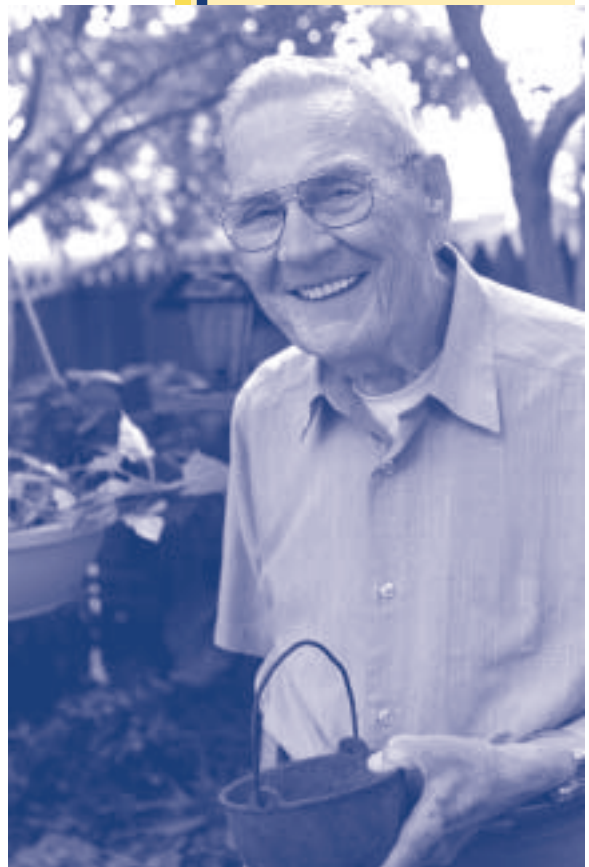
Texas Family Caregiver Support Program


DADS and its comprehensive aging network of 28 Area Agencies on Aging (AAA) and their local service providers administer the Texas Family Caregiver Support Program. Persons served under this program include individuals age 60 and older, individuals who care for person(s) age 60 and older, and grandparents caring for children under the age of 18.

While AAAs have historically provided support for caregivers, service has been limited in some areas of the state. The additional funding under the National Family Caregiver Support Program has allowed AAAs to expand services to more adequately meet the needs of caregivers in their community.

Conversations with caregivers across the country have identified critically needed components of a caregiver support program. These components fall under five priority areas:

- Information to caregivers about available services;
- Assistance in accessing services provided through care coordination and benefits counselors;
- Individual counseling, education, support group organization, and training to help caregivers make informed decisions and solve problems;
- Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and



 Texas
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Disease
Centers

Baylor College of
Medicine

Texas Tech University
Health Sciences Center

University of North Texas
Health Science Center

University of Texas
Southwestern Medical
Center

- Supplemental services to complement those provided by caregivers (e.g., nutrition, transportation, and health maintenance related items).

During FY 2005 and 2006, ninety-five percent of the funding provided through the National Family Caregiver Support Program goes directly to the state's 28 AAAs to provide direct services and support in the five areas identified above. The remaining five percent was used to fund five state level initiatives:

- A state caregiver support coordinator to manage the development and coordination of caregiver services and resources state-wide;
- Funding of community capacity building grants to enhance the infrastructure of caregiver services and support;
- Research related to the specific needs of caregivers, racial and ethnic differences in caregiving, and decisions caregivers make in using community resources and services;
- Training and consultation for individual caregivers and AAA benefits counselors in the areas of finance, guardianship, advance directives, and other caregiving issues; and
- Development of educational materials related to health, safety and well-being of both caregivers and care recipients.

Meeting the challenges of caregiving requires many resources. DADS and its 28 AAAs form an ideal network to provide comprehensive information and services for caregivers throughout the state. The Council and DSHS assist the Texas Family Caregiver Support Program through the development of educational materials targeted toward care recipients and caregivers, and marketing the program through our newsletter, website, and referrals.

Statewide Coordinated Research

In 1999, The 76th Legislature passed HB 1504, directing the Council to establish the Texas Consortium of Alzheimer's Disease Centers (Consortium). This bill has been codified in the Education Code, Chapter 154. The Consortium is composed of Alzheimer's Disease Centers at Baylor College of Medicine in Houston, Texas Tech University Health Sciences Center in Lubbock, University of North Texas Health Science Center in Fort Worth and the University of Texas Southwestern Medical Center in Dallas. The purpose of the Consortium is to create a systematic approach to the provision of uniform clinical services and to the sharing of research data. The following outcomes have been achieved through the Consortium:

- A shared clinical database for persons with AD has been developed. The purpose of this database is to facilitate clinical trials and other research related to AD. Data on patient outcomes is available to Consortium members, other clinicians and research-

ers, and appropriate state agencies. The database includes information concerning the prevalence and characteristics of AD in Texas and is useful for state planning purposes. Texans with AD and their caregivers are informed of any research projects and therapeutic trials open for their participation. The database was created in 2004, using 75 real research records from each of the Consortium member institutions. The Consortium Steering Committee hopes to increase this number as the funding strategy for the Consortium is implemented.

- Clinical services and education is available to patients and caregivers through the Consortium's clinical centers. This means that all Texans have access to optimal AD care. This results in significantly reduced costs to the state.
- Consortium members recommend directions for future research and public policy regarding persons with AD and their caregivers.

Since its inception, the Consortium Steering Committee has directed activities of the Consortium, with approval from the Council. A memorandum of understanding (MOU), outlining the roles and responsibilities of each of the participating institutions has been developed and approved by each institution. An operating plan, further detailing activities outlined in the MOU has been written and approved by the Council. In 2005, appropriated funds were approved by the legislature to implement the Education Code, Chapter 154 and further the activities of the Consortium. In 2006, the Council contracted with a Project Coordinator, approved a data coordinating system and hired a Research Epidemiologist.

The Consortium will provide an integrated approach toward identifying the cause(s) of AD, aggressive treatment modalities aimed at preventing and delaying the disease, and an eventual cure. A look at the individual research and clinical accomplishments of the four Consortium Member Institutions is a strong indicator of what can be achieved through their collaborative efforts.

Baylor College of Medicines Alzheimer's Disease Center

The Baylor College of Medicine's Alzheimer's Disease Center (ADC) provides clinical care and conducts both basic science and clinical research in AD and other forms of dementia. The center is recognized internationally for contributions related to the diagnosis and treatment of AD, as well as for contributions to the education of physicians, physicians in training, and other health service providers.

Researchers from the Baylor ADC have developed methods for studying inflammatory cells that are drawn to brain amyloid deposits, and have studied the biochemical interaction between these inflammatory cells and amyloid protein. Activated inflammatory cells secrete cytokines in an attempt to deal with the abnormal build up of amyloid protein.

C Texas onsortium of Alzheimer's Disease Centers



The Baylor ADC has been at the forefront for developing treatments for AD since 1987 . . .

The Texas Tech University Health Sciences Center (TTUHSC) has made a strategic commitment to the study and treatment of those disorders which especially affect the senior citizens of West Texas.

Researchers are measuring these cytokine levels in the blood and studying them in laboratory settings to help us understand the precise mechanisms of inflammation in AD brains. They are also collaborating with researchers at the University of Texas Southwestern Medical Center in their project to use specific isoforms of amyloid found in blood platelets as a marker of progression in AD.

The Baylor ADC has been at the forefront for developing treatments for AD since 1987, when the first successful drug for AD began clinical testing. Since that time, it was the lead site for the development of donepezil (Aricept), the most widely prescribed AD drug worldwide. Researchers helped to validate the use of rivastigmine (Exelon), and have studied the long-term benefits of a third approved AD therapy, galantamine (Reminyl). They have conducted studies to see if donepezil can be safely used in higher doses than are currently available, and whether the benefits of donepezil are as good for severe patients as they are for those with mild to moderate disease.

Baylor participated in a national multi-center study to test the combined benefits of donepezil and atorvastatin (Lipitor), a statin cholesterol-lowering drug. It is also conducting a separate trial of a different statin, simvastatin (Zocor) to test the theory that this particular form of statin, which readily enters the brain, may be more efficacious. Additionally, researchers conducted a study to assess the combined benefits of donepezil and memantine. They are also studying two treatment approaches in patients who have MCI, but do not yet meet the diagnostic criteria for AD, to see if disease can be forestalled or even prevented.

In addition to their work on therapies, ADC staff continue to diagnose and treat patients who suffer from AD and other forms of dementia. Baylor has published on the heterogeneity of AD, the fact that people can present with very different symptoms and follow very different courses once they are diagnosed. Specific areas of continued interest include projects that are done collaboratively with researchers from the University of Houston; and projects related to the neurobehavioral changes in AD, such as psychosis, for which the ADC collaborates with Baylor's Department of Psychiatry. They are also collaborating with the Veteran's Administration on health outcomes research, and with researchers from elsewhere in the country on clinical and translational research projects.

The Baylor ADC recently received a Zenith award from the National Alzheimer's Association to gather and analyze information about patients who are followed for many years at the center. They will use this information to create predictive models of disease progression, so that they can someday advise patients and their families in advance of what to expect.

Texas Tech University Health Sciences Center

The Texas Tech University Health Sciences Center (TTUHSC) has made a strategic commitment to the study and treatment of those disorders

which especially affect the senior citizens of West Texas. TTUHSC has set up Interdisciplinary Memory Disorders Clinics both at the Lubbock and El Paso campuses. Medical students and graduate students from Nursing and Family Medicine are taught in these clinics. Research is conducted in these clinics, having to do with the genetics of AD, the neurophysiology of memory, the epidemiology of memory disorders among Hispanic populations, and other topics.

In Lubbock and Amarillo, TTUHSC has established an Institute for Healthy Aging, to initiate a series of academic programs designed to improve the life quality of aging citizens in West Texas. The Institute has set up educational programs within all schools of the Health Sciences Center, and pilots research programs for clinical and basic science investigators.

The Lubbock campus has established close relationships with two long-term care facilities in order to develop innovative educational and research programs involving health care systems for the frail and demented elderly. The Garrison Center is a long-term care facility actually on the TTUHSC campus, built in partnership with the Sears Methodist Corporation. This 120-bed facility has 60 AD beds, and 60 non-Alzheimer's skilled nursing beds, and is used as a teaching facility for students from all schools. The Carillon Aging System, a contiguous aging facility has established a Research and Education Center for use by TTUHSC faculty and students. Through these two facilities, TTUHSC faculty hope to teach the next generation of healthcare workers about the rewards of providing long-term care to members of previous generations.

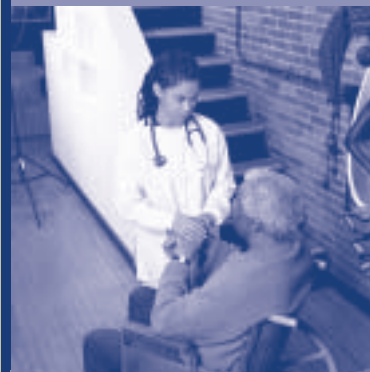
The University of North Texas Health Science Center

The University of North Texas (UNT) Health Science Center has a longstanding commitment to improving the care provided to the growing population of those over age 65. The Health Science Center was among the first in the country to offer specialized clinical care to older adults, medical training in geriatric care, and conduct research into aging issues. The Department of Medicine, Division of Geriatrics operates the Gerontology Assessment and Planning (GAP) Program. The GAP is an outpatient-based assessment program that utilizes a multidisciplinary team of physicians, social workers, and geriatric nurse specialists to thoroughly examine and assess the needs of the older adult. The GAP not only provides assessments to "well" older adults but also provides comprehensive assessments and care management services to persons with AD and their family members.

In an effort to meet the growing concern of baby boomers who have a family history of AD and/or are concerned about their occasional forgetfulness, the Division of Geriatrics, Department of Family Medicine and Special Projects on Aging operates a Memory Clinic. This clinic is designed as a single-stop for medical evaluation of memory disorders and the causes behind them.

Physician faculty members in the Division of Geriatrics also serve as

C Texas onsortium of Alzheimer's Disease Centers



The Health Science Center was among the first in the country to offer specialized clinical care to older adults, medical training in geriatric care, and conduct research into aging issues.

medical directors for numerous nursing and assisted living facilities in the North Texas area. Physicians within the Division of Geriatrics access this patient base to conduct numerous clinical trials related to AD.

Basic science research at the Institute for Aging and Alzheimer's Disease Research (IAADR) at the UNT Health Science Center is aimed at understanding why the body's defenses against oxidative damage appear to diminish with age, and which antioxidants may be the most effective. The goal of this type of research is to treat what is called preventable brain aging. Additional research is focused on 1) looking at the value of using various therapies, as well as behavior interventions, to preserve brain health, 2) estrogen therapy, and 3) the discovery of the mechanisms that lead to beta amyloid deposition and to neurofibrillary tangles.

The Special Projects on Aging Program coordinates a strategic alliance between clinicians and researchers at the UNT Health Science Center and supportive housing providers who serve residents with AD. The core effort of this program involves the collection of the resident's minimum data set (MDS) and evaluation of the MDS to develop accurate clinical indicators that can guide efforts to improve quality resident care. The program includes developing protocols for conducting clinical trials and basic science research studies, and provides medical and nursing staff specific training to address the physical, mental and psychological needs of the Alzheimer's patient.

The University of Texas Southwestern Medical Center Alzheimer's Disease Center

The Alzheimer's Disease Center (ADC) at UT Southwestern has developed several research programs directed at understanding the basis of memory loss and dementia in AD, as well as participating in collaborative national research clinical trials.

Studies have been conducted at UT Southwestern that looked at measuring real-time, moment-to-moment changes in regional brain metabolism. These studies are designed to test the response of the brain regionally with MRI to a specific visual learning stimulus. Normal subjects, patients with MCI, and patients with AD were studied. MCI patients developed a greater stimulus response than normal subjects and AD patients developed the largest stimulus response. These important observations show that the MCI and AD brain are progressively more inefficient in processing visual information and recalling it than normal subjects. This research quantifies regionally the defect in memory function in MCI and AD, and is a method to visualize memory ability in these disorders. It is a direct means to test the value of new AD drugs and their ability to reverse or slow this visualized inefficiency.



The ADC has developed a blood test to be used to diagnose AD and its progression over time.

The ADC has developed a blood test to be used to diagnose AD and its progression over time. It is based on the ratio of two proteins metabolized from the blood platelet amyloid precursor protein (APP). They have shown that the ratio of these two proteins decreases as AD dementia progresses in a linear manner over three years. Normal subjects, and patients with stroke and Parkinson's disease do not show a decline of this type over time. Further, they have shown that patients given cholesterol-lowering drugs have a stabilization of this ratio and normalization over time. Thus, this APP platelet blood test is an excellent candidate to be a biomarker in severity index to measure AD dementia progression, and a potential marker to test new therapeutic agents. Another study examines the effect of elevated serum homocysteinemia as a risk factor for developing AD and/or vascular dementia.

One other study focuses on apoptosis — neuronal cell loss due to the activation of a genetic program to eliminate specific cells in a disease process. AD tissue and neuronal cells in culture are being examined to see if this genetic program is important to understand cell loss in AD. It is an area of research that could lead to therapy directed at preserving cells and thus preventing AD.

Studies looking specifically at MCI are being conducted. One looks at the variations that can occur in patients having MCI, particularly the nonverbal form due to selective disease in the right hemisphere of the brain. It is a new concept for MCI, which has been studied only with language and standard verbal memory tests. Researchers at the ADC are studying drawing, symbolic stimuli, direction finding abilities and other non-language forms of recent memory functions. They are finding that at least one-third of MCI is mainly or exclusively occurring from the non-dominant right hemisphere of the brain. It is a new observation and important to understand the asymmetry and spectrum of dementing disease.

In addition to these research projects, clinical trials are ongoing with new drugs being developed by the pharmaceutical industry. The ADC is evaluating about 200 new AD patients yearly at their Memory/AD Clinic, and they are conducting clinical research with the Choctaw Nation of Talihina, Oklahoma. The ADC also educates patients and caregivers about AD throughout Texas and their five state region.

Advocacy

The Council, in its continued efforts to advocate on behalf of individuals with AD and their families, provides guidance to state agencies regarding program and policy decisions. In 2006, the Council authored a letter to the HHSC Pharmaceuticals and Therapeutics Committee recommending all five of the current Alzheimer's treatment drugs be included on the newly developed Medicaid Preferred Drug List. All five were included on the list although Cognex requires prior approval due to potential side effects. The Council was also very active in decisions made by DSHS executive management regarding staffing needs of the Alzheimer's Disease and Related Disorders Program, during the reorganization of HHSC agencies resulting from HB 2292.

Council Recommendations 2007 – 2008

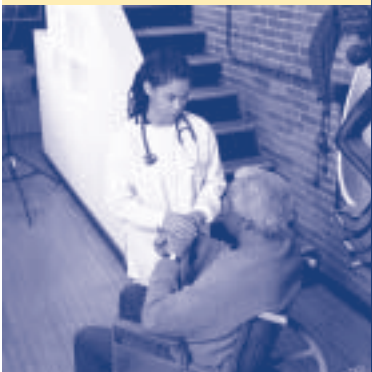
As the state's appointed advocates for persons with Alzheimer's disease (AD) and their caregivers, the Council respectfully submits the following recommendations.

Coordinated Statewide Alzheimer's Research

The Council requests the continued recognition and support of the importance of coordinated statewide research demonstrated by the Texas Legislature when it passed House Bill 1504, establishing the Consortium of Alzheimer's Disease Centers (Consortium). The Consortium provides the state of Texas with an infrastructure for sharing vital AD research information and clinical outcomes. It provides a framework for expanding and expediting the search for answers about the cause(s), methods to delay onset and stop disease progression, and eventual prevention and cure of AD.

Continued Support for Quality Long-Term Care

The Council supports maintaining current levels of nursing facility eligibility for people with AD. Specifically the Council requests maintenance of TILE codes 210 and 211 and/or work to redefine the TILE classes to accommodate a higher level of re-imbursment for facilities that care for persons with dementia. If AD were not covered by TILE, a person with Alzheimer's would not qualify for Medicaid nursing facility placement unless they had another co-existing medical condition or until they became more medically frail.



Council Recommendations 2007 – 2008

Expanded Community-Based Programs and Services

The Council supports expansion of home and community-based programs and services for individuals with AD and their caregivers. Family caregivers provide the vast majority of care provided to people with Alzheimer's. The Council supports expanded availability of affordable respite care, training for caregivers, and other resources to maintain the integrity of the family caregiving system. The recent elimination of the Community Alzheimer's Resources and Education (CARE) program left a significant gap in these services for the families who need them most. The Alzheimer's Association continues to provide services throughout Texas, but expanded resources would provide additional services to assist families in caring for their loved ones with Alzheimer's disease.

Continued support for and investment in coordinated statewide research, quality long-term care and expanded community-based programs and services offer the best return on investment in containing the economic and human costs of Alzheimer's disease.



Appendices

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

A

Texas Council on Alzheimer's Disease
and Related Disorders
2007 Conference Planning Committee

B

Texas Consortium of Alzheimer's Disease
Research Centers Steering Committee

C

Helpful Telephone Numbers and Web Sites

D

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

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Leon Douglas
Bertram

Carlos Escobar, MD
San Angelo

Charlene Evans, RN
Harlingen

Debbie Hanna, Chair
Austin

Grayson Hankins
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The Honorable Clint Hackney
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Davie Lee Wright Johnson
El Paso

Mary M. Kenan, Psy.D.
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Jack C. Kern, Vice Chair
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Margaret Krasovec
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Ray Lewis, DO
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Appendix B

Texas Consortium of Alzheimer's Disease Research Centers Steering Committee

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Dallas

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Baylor College of Medicine
Houston

Leon Douglas
Texas Council on Alzheimer's Disease and Related Disorders

Thomas Fairchild, Ph.D.
University of North Texas Health Science Center
Fort Worth

The Honorable Clint Hackney
Texas Council on Alzheimer's disease and Related Disorders

Debbie Hanna
Texas Council on Alzheimer's Disease and Related Disorders

Jack Kern
Texas Council on Alzheimer's Disease and Related Disorders

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Texas Tech University Health Sciences Center
Lubbock

Staff

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

Mary Somerville
Department of State Health Services
Austin

Helpful Telephone Numbers and Web Sites

External links to other sites are intended to be informational and do not have the endorsement of the Texas Department of State Health Services. These sites may be inaccessible to persons with disabilities.

ALZHEIMER'S ASSOCIATION **1-800-272-3900**

Information and referral services.

www.alz.org

- Comprehensive information for family caregivers, healthcare providers, researchers and the media on risk factors, diagnosis and treatment options; day-to-day care; legal and financial planning; insurance coverage; current research; and Association news releases.

www.alz.org/findchapter.asp

- Link to local chapters for available programs and services.

ALZHEIMER'S DISEASE CENTER AT BAYLOR COLLEGE OF MEDICINE **1-713-798-6660**

Clinical and basic science research; education; and diagnosis and treatment of patients with Alzheimer's disease and related disorders.

www.bcm.tmc.edu/neuro/struct/adrc/adrc1.html

- Drug trials; research projects; brain donation program; patient appointments and evaluation; and Alzheimer's disease information.

ALZHEIMER'S DISEASE CENTER AT UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER **1-214-648-7444**

Scientific research into the causes of Alzheimer's disease; and diagnostic evaluation of adult memory problems.

www.swmed.edu/home_pages/alzheimer/

- Clinical research studies; patient evaluation process; newsletters; educational events; and caregiver resources.

ALZHEIMER'S DISEASE EDUCATION AND REFERRAL (ADEAR) CENTER **1-800-438-4380**

Information about Alzheimer's disease, its impact on families and healthcare providers, and research into possible causes and cures.

www.alzheimers.org

- Research updates; directory of National Institute on Aging Alzheimer's Disease Centers; clinical trials database; recommended reading list for caregivers; and press releases.

MEDICAID HOTLINE **1-800-252-8263**

Toll-free number for general information and counseling on Medicaid.

www.hhsc.state.tx.us

- General information on Medicaid.

MEDICARE **1-800-633-4227**

National toll-free number for general information and counseling on Medicare.
www.medicare.gov

- Official U.S. government site for Medicare information on eligibility, enrollment, and premiums.
- Search tools for state-specific information on health plan choices; nursing home comparisons; prescription drug programs; participating physicians; and plan coverage.

**OFFICE OF THE ATTORNEY GENERAL
CONSUMER PROTECTION DIVISION** **1-800-621-0508**

Register complaints against businesses; report senior fraud.

www.oag.state.tx.us/elder/elder.shtml

- Senior Texans' page includes information on consumer protection; rights of the elderly; choosing a nursing facility; advance planning; health and safety; and Senior Alerts.

**TEXAS DEPARTMENT OF AGING & DISABILITY
SERVICE LONG TERM CARE REGULATORY** **1-800-458-9858**

Long-term care facility information; licensing and certification of facilities; and nursing facility complaints.

www.dads.state.tx.us/programs/ltc

- Information for consumers and providers on different types of long-term care facilities; quality ratings and comparisons; how to file a complaint about a facility; and provider training opportunities.

www.dads.state.tx.us/programs/ltc

- In-home and community-based services for individuals who are elderly or disabled, allowing them to remain in their own homes or communities.

TEXAS DEPARTMENT OF INSURANCE **1-800-252-3439**

Information; counseling; and filing a complaint against a private insurance provider.

www.tdi.state.tx.us/consumer/hicap/issues.html

- Health information counseling and advocacy; insurance fraud; and publications for seniors.

MENTAL HEALTH AND MENTAL RETARDATION **1-800-252-8154**

Consumer services and rights protection.

www.dshs.state.tx.us/agency/services_in_the_community

- Community programs, services and standards; and crisis hotline numbers.

**TEXAS DEPARTMENT OF FAMILY AND
PROTECTIVE SERVICES** **1-800-252-5400**

Hotline for reporting abuse, neglect, or exploitation of children, the elderly, or people with disabilities. Available 24/7.

www.dfps.state.tx.us

- Services for children, adults, and people with disabilities, including investigation of reports of abuse, neglect, and exploitation at home or in facilities licensed by state agencies; and arranging for protective services. Protective services may include referral to other programs; respite care; guardianship; emergency assistance with food, shelter, and medical care; transportation; and counseling.

TEXAS DEPARTMENT OF AGING & DISABILITY SERVICES **1-800-252-9240**
AREA AGENCY ON AGING INFORMATION AND ASSISTANCE

Routes calls to 28 Area Agencies on Aging in Texas that provide services for persons 60 years of age and older. Services include healthcare benefits counseling; case management; nutrition services; transportation; in-home help; senior centers; and the Retired Senior Volunteer Program (RSVP).

OMBUDSMAN PROGRAM **1-800-252-2412**
Investigates and helps resolve nursing home complaints. Helps with choosing a nursing home.

LEGAL HOTLINE FOR OLDER TEXANS **1-800-622-2520**
Legal assistance including counseling, representation, and document preparation.

www.dads.state.tx.us

- Links to 28 Area Agencies on Aging in Texas; Ombudsman Program; Residents' Rights; information on benefits counseling; caregiver resources; and free downloads of Agency brochures and reports.

TEXAS TECH UNIVERSITY HEALTH SCIENCES CENTER **1-806-743-3610**

Scientific research on Alzheimer's disease and aging; patient evaluation and care through their many clinics; and geriatric and long-term care education through The Institute for Healthy Aging.

www.ttuhs.edu/HSC/HOME/Researchindex.asp

Institute for Healthy Aging; DNA Bank; and patient care/clinical services for Alzheimer's disease and Parkinson's disease.

UNIVERSITY OF NORTH TEXAS HEALTH SCIENCE CENTER **1-817-735-5484**

Scientific research and clinical trials on Alzheimer's disease and aging; patient evaluation and care through their many clinics, including a specialty Memory Clinic; and geriatric education.

www.hsc.unt.edu/research/default.cfm

- Clinical trials; Geriatric Education and Research Institute; Consortium on Alzheimer's Research and Education; DNA Bank; and Memory Clinic.

**TEXAS DEPARTMENT OF STATE HEALTH SERVICES
ALZHEIMER'S DISEASE PROGRAM**

1-800-242-3399 • www.dshs.state.tx.us/alzheimers/alz.htm

Appendix D



Texas Council on Alzheimer's Disease and Related Disorders

Texas Department of State Health Services

1100 West 49th Street

Austin, Texas 78756-3199

512.458.7534 or 800.242.3399

www.dshs.state.tx.us/alzheimers

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