



2002
Biennial
Report

The Texas Council on
Alzheimer's Disease
and Related Disorders

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essage from the Chairman

On behalf of the Texas Council on Alzheimer's Disease and Related Disorders, I am pleased to present our 2002 biennial report of activities and recommendations. The Council was created by the Texas Legislature in 1987 to serve as the state's advocate for persons with Alzheimer's disease (AD) and those who care for them.

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

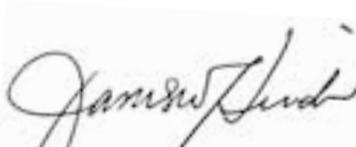
The imminent surge in the number of people with AD poses particular challenges and opportunities. For example:

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

research quality care

- Researchers are challenged to find ways to delay the onset of symptoms to later in the life span, as they work toward finding prevention and cure. People may live with a diagnosis of AD longer but with less disability and more independence.
- AD stakeholders are challenged to advocate for programs and services to support individuals with AD and family caregivers, and affordable quality care. 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 quality long-term care is critical as we work toward eradicating this devastating disease.



James W. Hinds, MPA
Chairman

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In Texas,
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The future of 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 diminishing 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, resulting eventually 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 from the onset of symptoms.

An estimated four million Americans have AD. With the current 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, in the absence of prevention or cure.

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, though some people in their 30s and 40s have been diagnosed with the disease. These prevalence rates take on increasing significance when we consider that the U.S. population older than 65 years 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. This has significant economic and human ramifications for an already burdened U.S. society.

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 costs to business 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 a loved one with AD, and are projected to be \$36.512 billion in 2002. The business share of healthcare for people with AD, plus taxes toward federal funding of AD research, are calculated at \$24.634 billion. The combined total equals \$61.146 billion. The study compares current figures to a similar study published in 1998, when business expenditures were calculated at \$33 billion for the year.² Costs have almost doubled in four years. Further, the 2002 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 1997 national survey conducted by the National Alliance for Caregiving and AARP pointed to 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.

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?

¹ Koppel, Ross. Alzheimer's Disease: The Costs 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.

In summary, 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.

Progress Through Research and Advocacy

Much has been learned about the pathophysiologic bases of AD, resulting in a more clearly recognizable clinical pattern. These 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 the loss of function that defines the transition into AD. Better understanding of the course and presentation of the disease has lead to earlier detection and more definitive diagnoses.

Scientists have also identified genetic and biologic changes that occur with AD, allowing them to pinpoint possible targets for treatment. Advances in pharmacologic treatment may stabilize and delay progression of AD symptoms for a year or more. 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 to postpone dependency.

Media reporting of ongoing research efforts and progress, coupled with strong advocacy from the Alzheimer's Association and other stakeholders, has put AD in the public eye. Increased public awareness and demand has led to a proposed 12% increase in the national research appropriation for FY 2003, by the Senate Appropriations Committee, as well as funding for family caregiver 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 individuals, families, and the economic system, and 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 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 illness. 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 remembering 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 underscored. The earlier the diagnosis, the more likely symptoms will respond to treatment. Additionally, many conditions with dementia-like symptoms are reversible. Further, early identification and aggressive treatment of AD offer the greatest opportunity for cost decreases through timely reduction in the rate of disease progression. Other factors to consider include safety of the individual with AD, opportunities for caregiver education, and advanced planning while the affected individual may still participate. A public health campaign aimed at educating individuals and families about the warning signs of AD and the benefits of early detection would be beneficial in the pursuit of earlier diagnoses.

Support for individuals with AD and their caregivers is also 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, including the Community Alzheimer's Resources and Education (CARE) Program and the Family Caregiver Support Program, is crucial because these programs afford caregivers the assistance they need to help keep their loved ones at home.

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 discovery and development to block progression of symptoms, delay the onset and eventually prevent AD is critical to decreasing morbidity and mortality, containing healthcare costs, and protecting individuals and families.

A public health campaign aimed at educating individuals and families about the warning signs of Ad and the benefits of early detection would be beneficial in the pursuit of earlier diagnoses.

⁴ Leon, J., Cheng, C.K., Neumann, P.J. Alzheimer's disease care: Costs and potential savings. *Health Aff*; 1998; 17:206-216.

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Texas Council on Alzheimer's Disease and Related Disorders

Background and Overview

Having the foresight to realize the imminent problem of age-related neurodegenerative diseases, the 70th Texas Legislative Session passed House Bill 1066, creating the Texas Council on Alzheimer's Disease and Related Disorders. 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; participate as a strategic partner and coordinating body for statewide education and research activities related to AD; and support policies and programs that will benefit people with AD and their caregivers.

The Council is composed of sixteen 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 four members representing respectively the Texas Department of Health, Texas Department on Aging, Texas Department of Human Services, and Texas Department of Mental Health and Mental Retardation.

In 1998, the Council 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.

Their activities over the years have reflected this four-pronged approach.

Council Activities

• *Awareness and Education*

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 has been its cornerstone. Texas Department of Health (TDH) staff, who support the Council and their work, maintain a toll-free information line for hundreds of individuals who call each month with questions about warning signs, diagnosis and possible treatments. Hundreds of comprehensive information packets are disseminated to the public each month and numerous referrals to local community services are made. Staff will research and find answers to difficult questions, and follow-up with individuals to assure they have been helped when referrals are made.

TDH staff also maintain a web site, 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 homes and assisted living facilities certified for the care of individuals with AD, and helpful toll-free phone numbers and Internet links. The web site is visited by more than 600 consumers each month. It may be accessed at www.tdh.state.tx.us/alzheimers/alz.htm.

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

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

Austin's DoubleTree Hotel was the setting for the Council's 2002 statewide biennial conference. Held on June 6 and 7, *Alzheimer's Care: Making a Difference in Everyday Life* presented the most current information available on the diagnosis and treatment of AD from some of the country's leading researchers. The program also featured innovations in care to improve the quality of life for individuals with AD and related disorders and their caregivers.

"In addition to presenting cutting edge research advances, we sought to demonstrate practical application of the findings," said Ellen MacDonald, Council Member and Conference Planning Committee Chair. "There is

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Advances in the pathogenesis of Alzheimer's disease have led to earlier diagnosis and new treatment strategies. Divergent from a traditional program theme of preparing for a death with dignity, *Alzheimer's Care* sought to focus on maintaining a sense of selfhood and dignity throughout the disease.

The June 6 opening plenary session featured Dr. Ronald Petersen, Mayo Clinic Alzheimer's Disease Center (ADC) Director; Dr. Roger Rosenberg, ADC Director at UT Southwestern Medical Center; and Dr. Rachele Doody, ADC Director at Baylor College of Medicine. Dr. Petersen compared and contrasted Mild Cognitive Impairment (MCI) and early stage AD, and described current assessment tools used to establish a differential diagnosis of dementia. He also discussed scientific advances in diagnosing AD early in the illness and the significance this diagnostic capability carries for the treatment and eventual prevention of memory disorders.

Dr. Rosenberg presented the latest advances in genetic research including new insights into how genes can interact to cause AD. He discussed new therapies for AD, including stem cell and somatic cell genomics. Dr. Doody explained the concepts of symptomatic and disease-modifying treatments, and described some of the strategies for future treatments designed to impact the neuropathologic changes in AD.

The featured luncheon speaker was Dr. Sharon Ostwald, Director of the Center on Aging at UT Health Science Center in Houston. Dr. Ostwald was a co-investigator with Dr. David Snowdon on the five-year pilot study for the widely acclaimed Nun Study. She discussed the longitudinal study and its implications for understanding AD, and leading longer, healthier and more meaningful lives.

Afternoon sessions on June 6 included Successful Activities to Enhance Quality of Life, Maintaining Selfhood and Dignity with Alzheimer's Disease, How Does Your Garden Grow – Horticultural Therapy, and Innovations in the Assessment and Treatment of Behavioral Disturbances. Speakers included Johnnie Elliott, Council Member and Administrator of the Rising Star Nursing Home; Mary Compton, President of Seasons Seminars in Dallas; Kim Nemec, Director of Programming for Uncommon Care/Barton House; Sharon Mobley, Operations Manager for Barton House; Audrey Chadwick, horticultural therapist; and Dr. Mark Kunik, Physician Investigator for the Houston Center for Quality of Care and Utilization Studies at the Houston Veterans Affairs Medical Center.

While both conference days had application for professional and family caregivers, June 7 was geared more specifically to lay caregivers. Dr. Ronald Devere, Medical Director of the Alzheimer's Disease Memory Disorders Center in Sugar Land and Seton Lakeway Center in Austin,

discussed the important issue of addressing the special healthcare needs of people with Alzheimer's disease. Assessment and diagnosis are particularly challenging when people are not able to clearly describe their pain or specific problem. Dr. Devere discussed appropriate communication techniques and methods to properly evaluate and address these needs.

Gary Jessee, Director of the Office of Area Agency on Aging Support and Operations at the Texas Department on Aging; Valerie Bridgeman Davis, Vice President of Programs for the Alzheimer's Association – Greater Austin Chapter; and Kim Nemec, Director of Programming for Uncommon Care/Barton House, presented a session on accessing respite care options. Respite care has been identified as one of the most pressing needs by families. The panel provided an overview of the various formal and informal respite options available to Texas caregivers, including their comparative benefits and barriers to accessing respite care.

Dr. Paul Chafetz, Clinical Geropsychologist and Adjunct Associate Professor at UT Southwestern Medical Center, concluded the two-day program with a presentation on healthy caregiving. In his discussion, Dr. Chafetz identified creative strategies for setting boundaries in one's daily caregiving role, and suggested ways to expand the caregiver circle to optimize care and prevent burnout.

More than 250 professional and family caregivers from across Texas and neighboring states attended the conference, giving the two-day program high ratings for overall content, quality of speakers, supporting materials, and organization. The conference proceedings handbook is available at the program's web site.

- *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 Texas Department of Human Services, the Texas Department on Aging, and the Texas Department of Mental Health and Mental Retardation. Both Council members and TDH 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 Community Alzheimer's Resources and Education (CARE) Program and the Texas Family Caregiver Support Program are two examples of Council collaboration and support.

CARE provides short-term assistance to help bridge gaps in services.



Community Alzheimer's Resources and Education Program (CARE)

CARE is a program that helps develop effective public and private partnerships to coordinate services and improve service delivery to persons with AD and their caregivers. The Council has been involved with this project since its inception in 1997 by participating in its planning, implementation and site monitoring. CARE services are available through the partnership of the Alzheimer's Association and the Texas Department of Human Services (DHS). A CARE case manager works with persons with AD and their caregivers to access needed services through public agencies and advocacy groups. A CARE case manager will take information over the phone to deem if the individual is eligible and if the person meets the criteria, the case manager will, with consent from the individual or caregiver, obtain a physician's statement of diagnosis where the doctor identifies the dementia-related diagnosis. Once the diagnostic form is received, the case manager will schedule an in-home visit.

CARE case management is available to persons (1) with a diagnosis of AD or a related disorder, and (2) who live in a county served by the program. Counties served include El Paso, Hudspeth, Floyd, Lubbock, Kleberg, Nueces, Parker, Tarrant, Gregg, Henderson, Smith, Fort Bend, Bell, Travis, Williamson, Cameron, Hidalgo, Willacy, Bexar, Gillespie, Kerr, Wharton, Colorado, and Brazoria. Services beyond case management are targeted to those who do not live in a care facility, have a financial need, and are without adequate family support. The case manager coordinates appropriate services available from agencies and organizations after an assessment of the client's needs is completed. The following are examples of short-term services that are available to CARE clients who have exhausted other resources:

- Adult day respite
- In-home respite
- Facility respite
- Safe Return registration
- Safety equipment
- Incontinence supplies
- Medication assistance
- Transportation

The CARE program is intended to provide short-term assistance to help bridge gaps in services. If the individual's needs are not readily met, the case manager will convene a CARE staffing. Here, members of agencies and organizations, which may be able to provide services, gather to share information, deliberate the service needs, and determine how to meet the special needs.

Following is a case study, which demonstrates how CARE was used to assist an individual with AD. Mrs. B was 83 and diagnosed with AD and cancer. Mrs. B had moved to the Austin area to live with her son and daughter-in-law, as she was no longer able to live alone due to her memory loss. When CARE made the home visit, Mrs. B was found to be indepen-

dent, able to carry out her activities of daily living, and not complaining of any pain. Because her only symptom was memory loss and she did not have any functional limitations apart from her diagnosis of cancer, there was concern that she might not qualify for in-home care through DHS. At her daughter's request, CARE made a referral to DHS for in-home care, adult day care, the Community Based Alternatives (CBA) Program, and Hospice. CARE provided in-home respite while the client awaited these services to begin.

CARE also provided registration for Mrs. B in the Alzheimer's Association Safe Return Program, as her daughter stated that the client had "gone for walks and gotten lost in the past." Additionally CARE provided the client's family with educational materials, such as *The 36-Hour Day* publication. About a month after the home visit, Mrs. B was alone at her son's home and had called the police and then walked away from the house. The family was able to locate the client and return home on their own, but they did call Safe Return as they were concerned that Mrs. B would not come home with them.

Mrs. B's family needed to go out of town the following month, and CARE provided a five day respite stay in an Alzheimer's unit at an assisted living facility. About a month after the respite stay, the family called the CARE Program to report that Mrs. B had been admitted to the Hospice facility, and 10 days later Mrs. B died.

CARE only served Mrs. B and her family for 3 months, but provided immediate services and filled the gap while waiting for long-term services to begin.

Here is another example of the CARE program at work. Mrs. A is 90 and diagnosed with dementia. She stays with her daughter and son-in-law in Austin half of the year and then goes to Beaumont to stay with her other daughter. The daughter in Austin had called DHS and requested in-home care for Mrs. A, asking CARE to provide in-home respite while awaiting DHS services to begin. Mrs. A's daughter worked from home but requested assistance to allow her to complete paperwork and run errands. CARE was able to provide in-home respite two days a week, for four hours each day. CARE also provided a respite video for the client to watch. The 25-minute video engages the client through music and recollection of fond memories. The caregiver, in turn, is able to enjoy short periods of "respite" or "time away" from the challenges of caregiving.

After completing the in-home assessment, the need for a transfer bath bench was identified and provided through CARE. CARE also registered the client in the Alzheimer's Association Safe Return Program, as the client does walk independently and is confused. CARE also provided Mrs. A's family with educational materials, including *The 36-Hour Day*.

Key to the overall effectiveness of the CARE program is a highly competent and dedicated case manager.

When home care through DHS began, CARE closed Mrs. A's case, but encouraged her daughter to contact CARE if the need should arise in the future. Mrs. A's daughter told the CARE case manager, "This respite care has really saved me!"

From the daughter's initial phone call to when the client's case was closed, CARE served Mrs. A and her family for seven months. CARE was able to provide immediate services and filled the gap while waiting for long-term services to begin.

While each client has a unique situation, all can potentially benefit from the specialized services that CARE provides. Key to the overall effectiveness of the CARE program is a highly competent and dedicated case manager. He/she links the individual in need with the programs and services that can help. He/she assesses and affords the interim assistance needed before long-term services can be implemented.



Family caregivers play a critical role in the long-term care system.

Texas Family Caregiver Support Program

The importance of CARE and other programs aimed at assisting individuals with AD and their caregivers is immeasurable. The critical role of caregivers continues to be recognized nationally and in Texas. In November 2000, Congress approved President Clinton's \$125 million request to expand caregiver support services under the Older Americans Act by funding a new National Family Caregiver Support Program. Texas received a total of \$6.1 million in FY 2001 and \$7 million in FY 2002 to assist informal caregivers in maintaining their caregiver roles.

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

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

Conversations with caregivers across the country have identified critical components of a caregiver support program. Services and programs 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
- Supplemental services to complement those provided by caregivers (e.g., nutrition, transportation, and health maintenance related items).

Almost all (95%) of the funding provided through the National Family Caregiver Support Program goes directly to the state's 28 AAAs to provide direct service and support in the five areas identified above. The remainder has been used to fund five state level initiatives:

- Hiring of a state caregiver coordinator to manage the development and coordination of caregiver services and resources statewide;
- Funding of community capacity building grants to enhance the infrastructure of caregivers services and support;
- Research related to the specific needs of caregivers; racial and ethnic differences in caregiving; urban and rural 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. TDoA and its 28 AAAs are committed to providing comprehensive information and services for caregivers throughout the state. The Council and TDH are committed to assisting the Texas Family Caregiver Support Program through the development of educational materials targeted toward care recipients and caregivers, and the marketing of this program through newsletters, the program's web site and referrals.

Caregivers need:

- Information about services
- Assistance in accessing services
- Counseling
- Education and training
- Respite care
- Support

House Bill 1504 Consortium of Alzheimer's Disease Centers

• *Statewide Coordinated Research*

In 1999, the 76th Legislature passed House Bill 1504, directing the Council to establish a Consortium of Alzheimer's Disease Centers (Consortium) in Texas. The Consortium is composed of Alzheimer's Disease Centers (ADC) at Baylor College of Medicine, Texas Tech University Health Sciences Center, University of North Texas Health Science Center, and the University of Texas Southwestern Medical Center. 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 Council expects that the following outcomes, important to all Texas residents with AD and their caregivers, will be achieved through the Consortium.

- A shared clinical database for persons with AD will be developed. The purpose of this database will be to facilitate clinical trials and other research related to AD. Data on patient outcomes will be available to Consortium members, other clinicians and researchers, and appropriate state agencies. The database will include information concerning the prevalence and characteristics of AD in Texas and will be useful for state planning purposes. Texans with AD and their caregivers will be informed of any research projects and therapeutic trials open for their participation.
- Clinical services and education will be available to patients and caregivers of the Consortium's clinical centers. This means that all Texans will have access to optimal care. This can result in significantly reduced costs to the state.
- Consortium members will recommend directions for future research and public policy regarding persons with AD and their caregivers.

Since its inception, a steering committee has been established to provide direction to the Council on activities related to the Consortium; a Memorandum of Understanding (MOU), outlining roles and responsibilities of each of the participating institutions, has been developed and approved; and an Operating Plan, further detailing activities outlined in the MOU, has been written and approved by the Council. Because appropriated funds did not accompany H.B. 1504, the Council has engaged in a number of efforts to secure monies to implement the provisions of the legislation. These efforts are ongoing.

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 each of the four Consortium sites is a strong indicator of what can be achieved through their collaborative efforts.

Baylor College of Medicine 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.

In past years, scientists from the Baylor ADC have studied the factors that cause amyloid protein to accumulate in the brains of AD patients, and how this accumulation leads to the death of brain cells. They 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. Researchers from the Baylor ADC 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. A better understanding of this process could lead to better treatments in the future. 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, they were the lead site for the development of donepezil (Aricept), the most widely-prescribed AD drug worldwide. They helped to validate the use of rivastigmine (Exelon), and have studied the long-term benefits of a third approved AD therapy, galantamine (Reminyl). They are currently conducting 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 is also involved in a national multi-center study to test the combined benefits of donepezil and atorvastatin (Lipitor), a statin cholesterol-lowering drug. They will do a separate National Institutes of Health (NIH) sponsored 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. Recently completed work with the drug memantine led to its approval in Europe, and they are just beginning enrollment in a study that assesses the combined benefits of donepezil and memantine.

Baylor was one of 20 sites worldwide to test the AN 1792 vaccine for the treatment of mild to moderate AD. Unfortunately, toxicity of this approach

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In addition to their work on therapies, ADC staff at Baylor continue to diagnose and treat patients with AD and other forms of dementia.

seen at some of the other sites led to a discontinuation of further injections, but they continue to follow these patients in order to learn more about the immune response and help to design future studies. They will participate in an NIH trial of several vitamin therapies to lower serum homocysteine levels in AD patients. 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. In the course of doing their clinical work, 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 patients who are more right brain affected or more left brain affected (hemispheric asymmetry), 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. They will also use this information to design clinical trials for new agents designed to slow the progression of AD. Such studies require information on the magnitude of change on certain test measures for groups of patients with specific characteristics, and this type of information is lacking in the medical literature. Baylor's studies will also examine whether differences in IQ or whether or not the patient has concurrent cerebrovascular disease make a difference in the subsequent progression of the disease. They will use this information collaboratively with academic researchers, as well as with industrial researchers, to help design appropriate clinical trials for promising therapies that have not yet entered clinical stages of testing.

Texas Tech University Health Sciences Center

Texas Tech University Health Sciences Center (TTUHSC) serves a broad range of ethnically diverse citizens across 200 counties in West Texas. Most of these citizens live in rural environments and in small towns. The changing demographics of Texas have increased the proportion of over 65 year olds among the 2.5 million people who live in this area, compared with East and South Texas. TTUHSC has made a strategic commitment to the study and treatment of those disorders which especially affect the senior citizens of West Texas.

AD is perhaps the most important disorder for the clinical departments and providers at TTUHSC. To assist people with memory disorders from AD and similar disorders, 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. This work is supported by grants from the Houston Foundation, the Paseo del Norte Foundation, the Alzheimer's Association, and the Administration on Aging.

In Lubbock and Amarillo, TTUHSC has established a new 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, with financial assistance from the Agency on Aging in Washington, has set up educational programs within all schools of the Health Sciences Center, and pilot 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. A contiguous aging facility, the Carillon Aging System, 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.

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The University Of North Texas Health Science Center

The University of North Texas (UNT) Health Science Center has a long-standing 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. Older patients have special needs because they may suffer from a variety of health problems and be taking multiple medications. In response to the older patient's complex needs, 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 operate 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 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.

Building on this faculty expertise and experience, the UNT Health Science Center was the first medical school in the Dallas-Fort Worth area to establish a geriatric fellowship program that offers physicians and dentists advanced training in caring for elderly patients.

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.

Special Projects on Aging coordinates the Consortium on Alzheimer's Research and Education (CARE) Program. This investigative program is a strategic alliance between clinicians and researchers at the UNT Health Science Center and supportive housing providers who serve residents

One goal of the
Institute for Aging
and Alzheimer's
Disease Research
at UNT is to treat
preventable brain
aging.

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. This education is also made available to other professionals in the community, caregivers, and students at the health science center.

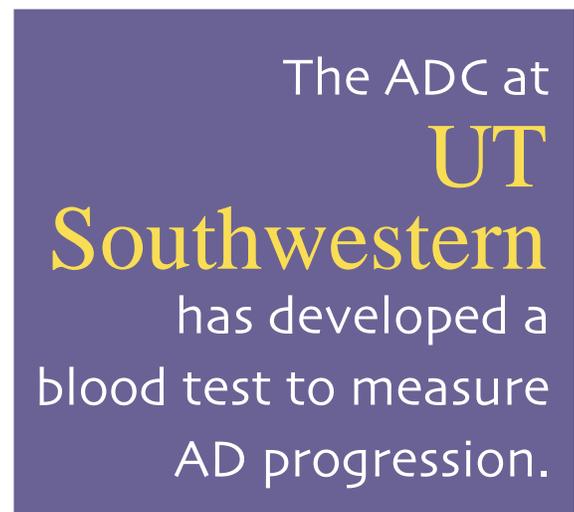
The University of Texas Southwestern Medical Center Alzheimer's Disease Center

The Alzheimer's Disease Center (ADC) at UT Southwestern has been effective in developing 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 are underway at UT Southwestern that are looking 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. 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 a normalization over time. Thus, this APP platelet blood test is an excellent candidate to be a bio-marker 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. The level of



The ADC at
UT
Southwestern
has developed a
blood test to measure
AD progression.

The ADC at UT Southwestern evaluates 200 new AD patients each year at their Memory/AD Clinic.

this amino acid will be measured in the serum of controls and AD patient patients to determine if there is a significant difference, and also to see if folic acid as a therapeutic agent can slow or prevent AD dementia from occurring.

There is ongoing research that examines the levels of two key enzymes, protein kinase and protein phosphatase 2A, to see how neuronal tangles form and disrupt the function of nerve cells in AD.

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 non-verbal form due to selective disease in the right hemisphere of the brain. It is a new concept for MCI, which as 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. In addition, 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.

The Consortium seeks to integrate the expertise and capacity of these four leading AD centers, and meet their shared goals of finding the cause(s), prevention and eventual cure for this debilitating disease.

- *Advocacy*

The Council, in its continued efforts to advocate on behalf of individuals with AD and their families, will initiate a new project in 2002-2003. The Council, in collaboration with its public and private partners, will conduct an awareness campaign aimed at increasing the early identification of individuals with AD. A task force has been formed and members will begin to develop a strategic plan for this project in the fall of 2002.

Council Recommendations

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

1) Consortium of Alzheimer's Disease Centers

The Council requests the continued recognition and support of the importance of statewide coordinated 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 the sharing of vital AD research 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.

2) Community-Based Programs and Services

The Council supports the continuation and expansion of home and community-based programs and services for individuals with AD and their caregivers. Specifically, the Council supports the availability of affordable respite care, training for caregivers, and other resources designed to maintain the integrity of the family caregiving system. The Council continues to support the Community Alzheimer's Resources and Education (CARE) Program, a partnership of the Alzheimer's Association and the Texas Department of Human Services, which provides case management and services to individuals in many rural counties in Texas.

3) Quality Long-Term Care

The Council supports increasing the reimbursement rate for nursing facilities to improve the quality of care by increasing wages and benefits for staff, and including dementia-specific training.

Continued investment in research, caregiver programs and services, and the provision of affordable quality care offer the best defense in containing the economic and human costs of AD.

**Statewide
coordinated
research/
Community-based
programs and
services/Quality
long-term care**

Appendices



Texas Council on Alzheimer’s Disease and Related Disorders Member Roster



Conference Planning Committee Member Roster



Consortium Steering Committee Member Roster



Helpful Telephone Numbers and Web Sites

Texas Council on Alzheimer's Disease and Related Disorders

2002 Member Roster

Appendix

A

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Rising Star

Charlene Evans, RN
Harlingen

James W. Hinds, MPA, Chairman
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Baylor College of Medicine
Houston

Jack C. Kern
Austin

Minnie Lee Lancaster, MD
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Austin

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Texas Department on Aging
Austin

Staff

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Austin

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

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Appendix B

Appendix



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2002 Member Roster

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Austin

Mary Somerville
Texas Department of Health
Austin

Helpful Telephone Numbers and Web Sites

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 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.

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. Includes general information on eligibility, enrollment, and premiums. Includes search tools for state-specific information on health plan choices; nursing home comparisons; prescription drug programs; participating physicians; and plan coverage.

http://cms.hhs.gov/

- Centers for Medicaid and Medicare Services (formerly called Health Care Financing Administration). Includes general information on Medicaid and Medicare.

Appendix D

**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 home; advance planning; health and safety; and Senior Alerts.

**Texas Department of Health Alzheimer's Disease Program
1.800.242.3399**

Information and referral to local services.

www.tdh.state.tx.us/alzheimers/alz.htm

- Statistics and information on warning signs, diagnosis and treatment of Alzheimer's disease.
- Options for care.
- Lists of licensed nursing homes and assisted living facilities in Texas that are certified for the care of persons with Alzheimer's disease and related disorders.
- Legal and financial issues.
- Downloadable version of Texas Alzheimer's News newsletters.

**Texas Department of Human Services
Long Term Care Regulatory
1.800.458.9858**

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

www.dhs.state.tx.us/programs/ltc/index.html

- 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.dh.state.tx.us/programs/

- In-home and community-based services for individuals who are elderly or disabled, allowing them to remain in their own homes or communities.
- Community Alzheimer's Resources and Education (CARE) Program.

**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.

Texas Department of Mental Health and Mental Retardation

1.800.252.8154

Consumer services and rights protection.

www.mhmr.state.tx.us/Agency/ServicesInTheCommunity.html

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

Texas Department of Protective and Regulatory Services

1.800.252.5400

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

www.tdprs.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 on Aging

Area Agency on Aging Information and Assistance

1.800.252.9240

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.tdoa.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 Council on Alzheimer's Disease and Related Disorders

Texas Department of Health
1100 West 49th Street
Austin, Texas 78756-3199
1.512.458.7534 or 1.800.242.3399
www.tdh.state.tx.us/alzheimers/alz.htm

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