



Winter 2002



Texas Alzheimer's News

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

Early Diagnosis Key to Fighting Alzheimer's Disease

"I'm having a senior moment!"

That's become the half-joking, half-worried wisecrack of aging baby boomers – hinting at the possible onset of Alzheimer's disease. But when does absentmindedness – like forgetting where you put your car keys – become something requiring diagnosis and treatment?

Alzheimer's disease is an age-related, degenerative brain disorder that causes severe enough problems with memory, thinking, and behavior to interfere with everyday life. Over time – and this is the frightening part for most people accustomed to their independence – as cognitive and functional abilities decline, individuals are rendered dependent on others for all of their care. Eventually body functions shut down and they succumb to death.

The Alzheimer's Association has developed a checklist of common warning signs of Alzheimer's disease, and recommends consulting a physician if you recognize any

of these symptoms in yourself or a loved one:

- Memory loss that is worsening;
- Difficulty performing familiar tasks, such as preparing a meal or participating in a lifelong hobby;
- Problems with language, such as forgetting simple words;
- Disorientation to time and place;
- Poor or decreased judgment;
- Problems with abstract thinking, such as balancing a checkbook;
- Misplacing things – anyone can temporarily misplace a set of keys. A person with Alzheimer's disease may put things in unusual places, e.g., a set of keys in the freezer;
- Abrupt changes in mood or behavior;
- Changes in personality – becoming extremely confused, suspicious or fearful; and/or,

- Loss of initiative – increasing disinterest and apathy.

For many years, people were often reluctant to seek a diagnosis of Alzheimer's disease, preferring not to know because there was little that could be done. Thinking has changed – there now is hope and a sense of urgency for the early diagnosis of Alzheimer's disease.

New drugs may help delay the progression of symptoms associated with the disease, and they are most effective when started at earlier stages.

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Early diagnosis can afford individuals with Alzheimer's disease the opportunity to help plan their own treatment and care plan, and it gives them time to put their financial and legal documents in order. Community-based programs and services offer valuable assistance to family caregivers.

Over the years, diagnostic tools have greatly improved. There now is a 90 percent accuracy rate in diagnosing Alzheimer's disease. In evaluating an individual for possible Alzheimer's disease, health care providers can help rule out other disorders that share similar symptoms, like stroke, brain tumor, thyroid problems, and substance abuse. Many of these conditions are reversible and best if treated early.

Alzheimer's disease affects up to 10 percent of people at age 65. Those odds increase to one in two people at age 85 or older, though some people in their 30s and 40s have been diagnosed with the disease. This age-related, progressively debilitating disease currently affects four million Americans. In the absence of prevention or cure, it is projected that there will be 14 million people with Alzheimer's disease by the middle of this century.

In the meantime, early diagnosis is important. The earlier the diagnosis, the more likely symptoms will respond to treatment. Because some individuals with Alzheimer's do

not realize they have a problem, it may be up to a family member or friend to help them make and keep a doctor's appointment.

The Texas Council on Alzheimer's Disease and Related Disorders has begun a pilot project to increase awareness about the importance of early diagnosis. The Council is initially targeting baby boomers, who are at a pivotal age where they can look for warning signs in their parents, become more self-aware, and increase awareness among younger generations. Awareness campaign updates will be provided in subsequent newsletters and on the Council's web site: www.tdh.state.tx.us/alzheimers/alz.htm.

Education in Action

by Sarah Jackson

There are over 280,000 Texans living with Alzheimer's disease. This number will rise to over 500,000 by 2025. The mission of the Alzheimer's Association Coalition (AACT) is to advocate for the improved quality of life for Texans affected by Alzheimer's disease. The Coalition, which represents five Alzheimer Association chapters and 11 regional offices, is committed to accessible, affordable, quality care for people with Alzheimer's disease and their caregivers in Texas.

The AACT has been diligently educating and advocating across the state. With the 78th legislative session upon us, Coalition members have been strategizing about how to effectively make changes for hundreds of thousands of Texans. With a looming budget deficit, many may wonder what can be accomplished for the over 280,000 Texans and their caregivers who live with the progressively debilitating and ultimately fatal disease.

The AACT is committed to:

- **Promoting and preserving home and community-based services.** Public funding for long-term care programs is biased in favor of institutional settings, yet 70 percent of all people with Alzheimer's disease live at home, and family and friends provide 75 percent of all care at no expense to the state. The AACT recommends continued funding of the Community Alzheimer's Resources and Education (CARE) Program. CARE is a unique public-private collaboration between the state and the Alzheimer's Association. The program targets people with Alzheimer's disease and their families who need community and home support services. There are currently nine sites in Texas with the long-term goal of establishing sites statewide.

- **Enhancing quality care in long-term care facilities.**

The AACT recommends increasing the reimbursement rate to nursing home facilities and community-based programs, and providing dementia-specific training for direct care staff. An increase in wages and benefits to staff, and developing incentives, such as wage increases and bonuses for staff who attend extra training sessions, can help improve the quality of care.

- **Revising the method of state reimbursement to nursing homes to adequately reflect the care needed for residents with Alzheimer's disease.**

Currently, the state uses a system called Texas Index for Level of Effort, or TILE, to reimburse nursing facilities. This system is based on an antiquated study conducted over 15 years ago when the population living in nursing facilities needed more rehabilitative services rather than behavioral management. A study should be completed to determine current resource requirements in caring for people with dementia. The AACT supports a TILE system that adequately reimburses for people with dementia in the areas of behavioral symptoms, cognitive impairment, supervision, and cueing. The TILE reimbursement levels

should recognize that, while the condition of people with dementia may not improve, their quality of life should be maintained and their caregivers appropriately reimbursed.

The AACT is sponsoring an Alzheimer's Day at the Capitol on February 18, 2003 at the Crowne Plaza in Austin. This day provides an opportunity for families, professionals, and people with Alzheimer's disease to voice their needs and concerns to their elected officials. For more information on how you can participate or to register for Alzheimer's Day at the Capitol, contact Sarah Jackson by calling 512.241.0420 or via email: sarah.jackson@alz.org.

Sarah Jackson is the Director of Public Policy for the Alzheimer's Association Coalition of Texas



Resources

Advocacy, Inc.

www.advocacyinc.org/
Advocacy, Inc., with offices throughout Texas, is a non-profit corporation established to protect and advocate for the legal rights of people with disabilities in Texas. Advocacy, Inc. provides information and materials on disability related issues, as well as referrals to programs and

services for people with disabilities. This agency also provides services to represent individuals, e.g., investigation, mediation, negotiation, and legal representation. In addition, systems advocacy services are provided, including training for people with disabilities on their rights and how to advocate for themselves, and technical assistance for lawyers and private service providers.

American Association for Retired Persons (AARP)

www.aarp.org/

AARP is a nonprofit membership organization dedicated to addressing the needs and interests of persons 50 and older. Through information and education, advocacy and service, AARP seeks to enhance individuals' quality of life by promoting independence, dignity and purpose. AARP provides information and education, legislative, legal and consumer advocacy at the national, state and local levels, volunteer opportunities, and products and services. AARP advocates for people aged 50 plus on issues such as patient rights in long-term care and prescription drug coverage through Medicare. Web site includes information on health and wellness, policy and research, legislation, and many other topics, including a page entitled "life answers," which includes a long list of caregiver resources. Texas State Office phone number: 512.480.9797.

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National Family Caregiver Association (NFCFA)

www.nfcacares.org/

NFCA was created to educate, support, empower and speak up for the millions of Americans who care for chronically ill, aged, or disabled loved ones. NFCA reaches across the boundaries of different diagnoses and different life stages to address the common needs and concerns of all family caregivers. Through its services in the areas of information and education, support, public awareness and advocacy, NFCA strives to minimize the disparity between a caregiver's quality of life and that of mainstream Americans. Web site includes tips for caregiving and many articles and publications aimed at self-empowering caregivers.



Events

Alzheimer's Association Hosts Annual Public Policy Forum

"Alzheimer Advocacy: Many Voices, One Message," is the theme for the Alzheimer's Association 2003 Public Policy Forum. Health professionals, family caregivers, persons with Alzheimer's disease and other advocates will converge at the Capital Hilton Hotel in Wash-

ington, D.C. March 29-April 1, 2003 with a shared vision and goals – to raise awareness about Alzheimer's disease, to advance research, and to enhance care and support for those with the disease and their caregivers.

The forum will include general sessions addressing the latest advances in dementia research and the power of advocacy in changing health care practice and policy, and will equip advocates with the skills and tools needed to talk with legislators. Workshops will include such topics as Medicare reform, enhanced care training, prescription drugs, and dealing effectively with the legislature. Additionally, individuals with early-stage Alzheimer's disease will discuss their first-hand experiences.

Advocacy is a major component of the Alzheimer's Association mission to achieve a world without Alzheimer's disease. The Association is regarded as an authority on issues affecting people with Alzheimer's disease and those who care for them. The Public Policy Forum has been held each year since 1989. The Association's major advocacy priorities are increased research funding, Medicare reform, and enhanced long-term support for individuals with Alzheimer's disease and their families.

For more information on the 2003 Public Policy Forum, call 202.393.7737 or visit www.alz.org/PublicPolicy/overview.htm.

Alzheimer's Association Coalition of Texas Hosts Alzheimer's Day at the Capitol

February 18, 2003 is the date Texas Alzheimer's advocates will flock to the State Capitol to voice their concerns about policies affecting individuals with Alzheimer's disease and their caregivers. Key issues include: promoting and preserving home and community-based services, enhanced quality of care in long-term care facilities, and revising the method of state reimbursements to nursing homes to reflect care needed by residents with Alzheimer's disease.

Advocates will convene at the Crowne Plaza Hotel in downtown Austin to prepare for their visits to legislators. Registration is at 8:30 am. From 9:00 am to 1:00 pm, participants will be briefed on the Coalition's legislative platform and receive important advocacy tips. At 1:30 pm, a shuttle bus will take advocates to the Capitol for visits with their legislators. All are reminded to contact the Executive Chapter of their local Alzheimer's Chapter to schedule appointments with their legislators.

For more information, contact Sarah Jackson by calling 512.241.0420 or via email: sarah.jackson@alz.org.

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National Education Conference Planned for July

The National Alzheimer's Association will host their biennial education conference on July 20-23, 2003 in Chicago. The 2003 conference will focus on the changing face of Alzheimer's disease, providing person-centered care as the disease progresses, developing quality staff and providing quality care, and improving care systems.

The conference gives individuals with Alzheimer's disease and their caregivers the opportunity to learn about advances in research and care from leading experts, while networking with more than 1,500 participants. The program includes plenary, poster and breakout sessions, peer-facilitated roundtable discussions, film viewings and discussion, and exhibitors displaying the latest in Alzheimer's disease treatment and care.

Registration materials will be available in mid-March. Visit the National web site at: www.alz.org.

Caregiver Tips

Caring for a person with Alzheimer's disease at home is a difficult task and can become overwhelming at times. Each day brings new challenges as the caregiver copes with changing levels of ability and new patterns of behavior. Research has shown that caregivers themselves often are at increased risk for depression and illness. Here are some caregiver tips to help add balance to your life.

- Take good care of yourself. Take time to nurture yourself daily with a healthy diet, exercise, and adequate rest.
- Establish daily routines. Organize responsibilities into a checklist of small doable tasks.
- Get organized. Keep all of your loved one's important information in one easily accessible place. Be sure to include medical, legal, and financial information, e.g., insurance cards, advance directives, social security information, etc.
- Access community programs and resources. Contact your local Alzheimer's Association about caregiver support groups, the Community Alzheimer's Resources and Education (CARE) Program, and other services they provide. Call your local

Area Agency on Aging to learn about services for Texans who are 60 years of age and older and the Texas Family Caregiver Support Program.

- Ask your friends and family for help. Be specific about what you need and when you need it.
- Make time for yourself. Read a book, take a walk, meditate, listen to music....take the time to do something you enjoy.
- Stay connected. Take the time to be with friends. They can provide you with the understanding, support, and perspective you need.
- Keep your sense of humor.
- Pat yourself on the back. Remember to give credit to and appreciate yourself for all the roles you perform and all of the tasks you carry out. Caregivers are creative, resourceful, generous, sensitive, and special people.



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

The Coalition represents the five chapters and 11 regional offices of the Alzheimer's Association in Texas, and their regional offices. The Alzheimer's Association is a national voluntary health organization founded in 1980 to provide information and services, including a telephone help line, family support groups, educational programs, a lending library, the Safe Return program for wanderers, in-service training, and multicultural outreach programs. The mission of the Coalition is to advocate for the improved quality of life for Texans affected by Alzheimer's disease and related disorders.



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

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

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

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

Council Report Available Online

The 2002 Biennial Report of the Texas Council on Alzheimer's Disease and Related Disorders is currently available on the Council's web site:

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

Please feel free to download the report. If you would like to have a printed copy of the report mailed to you, please call 800.242.3399 or 512.458.7534.