



# Texas Alzheimer's News

A publication of the  
Texas Council on Alzheimer's Disease and Related Disorders



## Principles for a Dignified Diagnosis of Dementia

In recognition of the changing landscape of Alzheimer's, the Alzheimer's Association hosted four regional town hall meetings with more than 800 participants, including 300 people living with the disease. The 2008 report *Voices of Alzheimer's Disease* examined the rich dialogue at these town halls and identified diagnostic challenges and dissatisfying interactions with the medical community as two major challenges articulated by people living with the disease. The new, innovative *Principles for a Dignified Diagnosis* contains insights from people living with the disease on how to improve that experience.

"Patients with Alzheimer's disease face many challenges as they strive to maintain a normal life, and physicians are committed to helping ease the burden with high

quality health care," said American Medical Association president Nancy Nielsen, M.D. "The AMA applauds the Alzheimer's Association for bringing forward the patients' perspective on compassionate care, as Alzheimer's patients, their families and their physicians battle the disease together."

Dr. Steve Hume, a member of the Alzheimer's Association Early Stage Advisory Group and a co-author of *Principles for a Dignified Diagnosis*, was diagnosed with younger-onset Alzheimer's disease in May 2007 at the age of 61. Prior to his diagnosis, Steve was a clinician, consultant and senior manager in the behavioral health field. Despite his professional health background, Steve struggled to secure a complete diagnosis. In fact, the first neu-

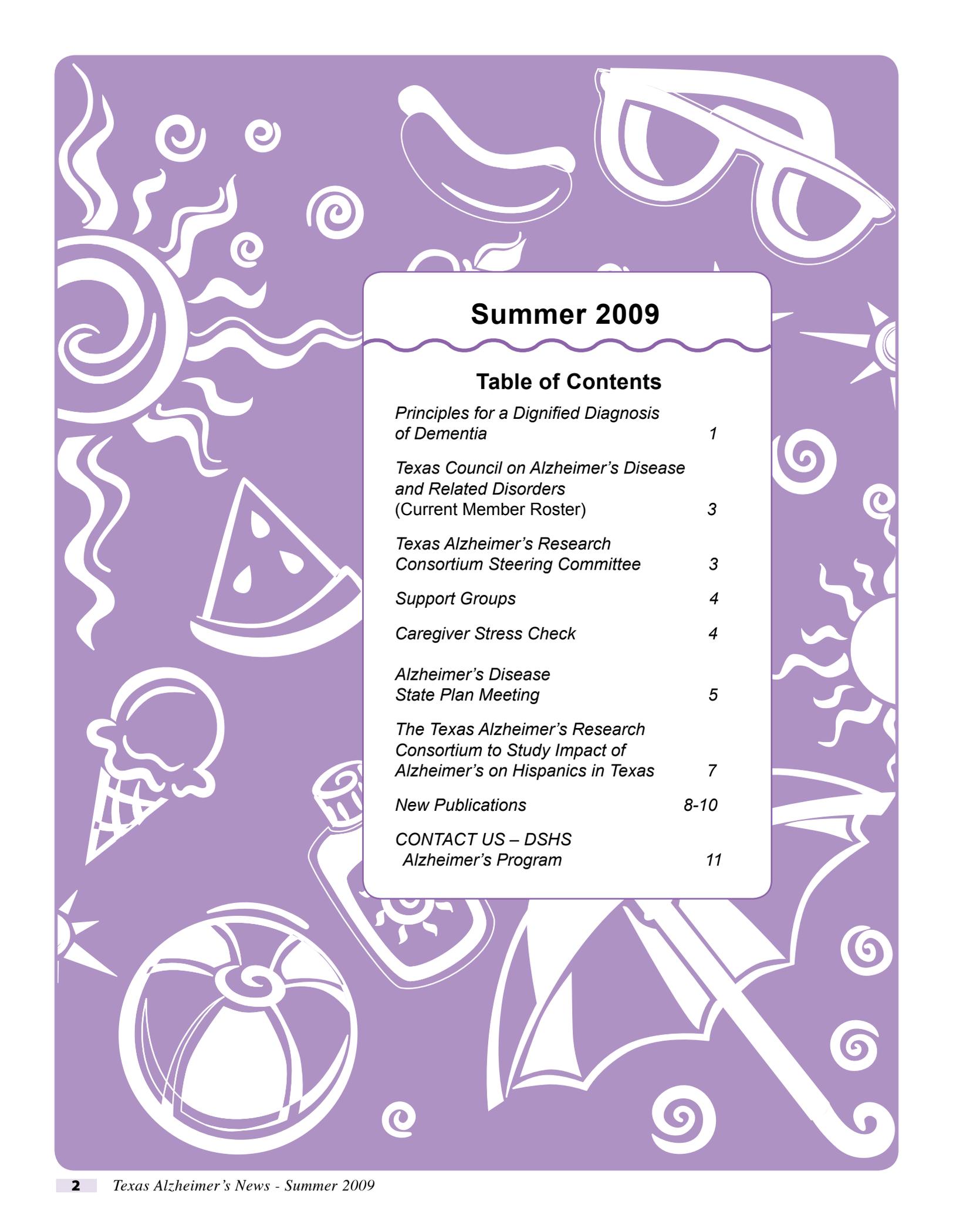


rologist he visited told him he'd be fine if he just lost weight.

"The face of Alzheimer's has changed in recent years, and *Principles for a Dignified Diagnosis* adds a voice to that face," said Dr. Hume. "It is important that we not only tell clinicians we want a dignified diagnosis, but also teach them what that means. There is a lot we can learn from each other."

### The Principles for a Dignified Diagnosis include the following:

- **Talk to me directly, the person with dementia.** I am the person with the disease, and though my loved ones will also be affected, I am the person who needs to know first.
- **Tell the truth.** Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.
- **Test early.** Helping me get an accurate diagnosis as soon as possible gives me more time to cope and live to my fullest potential and to get information about appropriate clinical trials.
- **Take my concerns seriously, regardless of my age.** Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because I am old. At the same time, don't forget that Alzheimer's can also affect people in their 40s, 50s and 60s.



## Summer 2009

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# Texas Council on Alzheimer's Disease and Related Disorders

## Current Member Roster

### Appointed Members

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## TEXAS ALZHEIMER'S RESEARCH CONSORTIUM STEERING COMMITTEE

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University of North Texas  
Health Science Center  
Fort Worth, Texas

### Dr. Donald R. Royall, M.D.

University of Texas  
Health Science Center  
San Antonio, Texas

The Texas Council on Alzheimer's Disease and Related Disorders was established in 1989 by the Texas Legislature 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.

The Council has adopted as its 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.



TARC Steering Committee members Dr. Rachelle Doody, Baylor College of Medicine and Dr. Donald Royall, University of Texas Health Science Center at San Antonio speaking at a Capitol press conference announcing the new TARC research focus on Hispanics.

# Caregiver Stress Check

If you are a caregiver of someone with AD, taking time to care for yourself is just as important as your care giving role.

If you find that care giving is affecting your physical or emotional health, please call your local Alzheimer's Association.

## Do you regularly . . .

1. Feel like you have to do it all yourself, and that you should be doing more  Yes  No
2. Withdraw from family, friends and activities that you used to enjoy  Yes  No
3. Worry that the person you care for is safe  Yes  No
4. Feel anxious about money and healthcare decisions  Yes  No
5. Deny the impact of the disease and its effects on your family  Yes  No
6. Feel grief or sadness that your relationship with the person isn't what it used to be  Yes  No
7. Get frustrated and angry when the person with dementia continually repeats things and doesn't seem to listen  Yes  No
8. Have health problems that are taking a toll on you mentally and physically  Yes  No



## Support Groups

Support groups are a vital service for those who care for people with Alzheimer's disease.

For some, attending a support group can be difficult at first, but the benefits of meeting and sharing with fellow caregivers can be a great source of strength.

To find a support group in your area, please call your local Alzheimer's Association, or visit [www.alz.org](http://www.alz.org).

To take the stress check online and then get resources that can help, visit the following webpage:  
<http://www.alz.org/stresscheck/>

# Alzheimer's Disease State Plan Meeting



In June 2009, the Texas Alzheimer's Disease Program at the Department of State Health Services, the Texas Council on Alzheimer's Disease and Related Disorders, and the Alzheimer's Association Chapters in Texas sponsored the Texas Alzheimer's Disease State Plan Partnership Meeting to begin the development process for the first coordinated Texas state plan on AD. Over 80 public and private stakeholders attended this meeting, representing the expertise of diverse partners from the state, community, organizational, healthcare and academic sectors.

Through January 2010, the partnership will continue their work to develop a comprehensive and statewide plan that identifies and coordinates the use of state, local and federal resources in reducing the impact of this disease. The plan is scheduled to be available in May 2010.

State Plan Goals include:

1. Texans will experience preserved cognitive health throughout the life span.
2. Texans will experience improved quality of care by strengthening state and local capacity to address AD across the continuum of care.
3. Texans with Alzheimer's disease will experience improved quality of life through better disease management.
4. Caregivers will experience enhanced levels of support through improved access to information and services.
5. Texas will support Alzheimer's disease research.

If you would like to participate in the development of the plan, please contact Susan Ristine by e-mail at [susan.ristine@dshs.state.tx.us](mailto:susan.ristine@dshs.state.tx.us) or by phone at 512-458-7111, ext. 2458.

## The Principles for a Dignified Diagnosis include the following

- Deliver the news in plain but sensitive language. This may be one of the most important things I ever hear. Please use language that I can understand and is sensitive to how this may make me feel.
- Coordinate with other care providers. I may be seeing more than one specialist — it is important that you talk to my other providers to ensure you all have the information so that changes can be identified early on and that I don't have to unnecessarily repeat any tests.
- Explain the purpose of different tests and what you hope to learn. Testing can be very physically and emotionally challenging. It would help me to know what the purpose of the test is, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.
- Give me tools for living with this disease. Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Alzheimer's Association and other resources in my community.
- Work with me on a plan for healthy living. Medication may help modify some of my neurological symptoms, but I am also interested in other recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.
- Recognize that I am an individual and the way I experience this disease is unique. This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.
- Alzheimer's is a journey, not a destination. Treatment doesn't end with the writing of a prescription. Please continue to be an advocate — not just for my medical care but for my quality of life as I continue to live with Alzheimer's.

The *Principles for a Dignified Diagnosis* will build greater understanding of Alzheimer's disease in the medical community," said Dr. Laurel Coleman, Alzheimer's Association national board member. "Since Alzheimer's is a progressive brain disease, the physical, emotional and social implications of the diagnosis need to be considered throughout the journey."

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's.



For more information, visit <http://www.alz.org/>

Contact: Alzheimer's Association • Media line: 312.335.4078 • E-mail: [media@alz.org](mailto:media@alz.org)

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# State Increases Funding for Alzheimer's Research Research Consortium to Study Impact of Alzheimer's on Hispanics in Texas

By Jim Hinds, *Project Coordinator, Texas Alzheimer's Research Consortium*

With \$6.85 million in new state funding awarded for Alzheimer's research through 2011, the Texas Alzheimer's Research Consortium (TARC) is embarking on a new research focus on the impact of Alzheimer's disease on Hispanics.

Funding is now available to add a fifth research institution—The University of Texas Health Sciences Center at San Antonio — to the Consortium and build on our work to find blood biomarker and genetic triggers to help better diagnose, slow progression, and ultimately prevent Alzheimer's disease.

In April, Justice Sandra Day O'Connor addressed the Texas Senate and challenged our state and nation to target Alzheimer's for research breakthroughs with the same intensity and commitment that reined in the spread of polio and TB in the 1950s. Justice O'Connor retired from the U.S. Supreme Court in 2006 to care for her husband who has Alzheimer's.

The State of Texas is rising to this challenge by funding the TARC over the next two years at a level that exceeds all state funding for the Consortium since 2005, the historic year when the first state dollars were committed for Alzheimer's research. Today, almost 340,000 Texans are living with Alzheimer's disease. Without research breakthroughs, Alzheimer's will reach epidemic proportions by 2050.

These original four Consortium member institutions have lost no time in recruiting about 800 research volunteers from across the state: 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.

Over the next two years, we anticipate enrolling another 400 research volunteers.

The fastest-growing segment of the Texas population is Hispanic, making it imperative that we address their susceptibility to Alzheimer's. Hispanics are under-represented nationally in Alzheimer's research — and Texas now has an opportunity to lead the country in this work.

With the addition of The University of Texas Health Sciences Center at San Antonio to the TARC, Texas has an unprecedented opportunity to quickly assemble the nation's only large, well characterized body of Caucasian and Hispanic/Mexican-American Alzheimer's research subjects—making the Consortium highly competitive for external grant funding.

One of the TARC's greatest strengths is its capacity to study disease progression in research volunteers over time. By uniformly collecting a wealth of genetic, psychometric and blood tissue data in its centralized Texas Alzheimer's DataBank, our TARC researchers can mine this information to explore possible links between Alzheimer's and cardiovascular disease, diabetes, inflammation and depression.

Already TARC researchers have succeeded in identifying a simpler, more accurate way to measure smaller incremental changes in dementia progression — potentially making it possible to differentiate between

Mild Cognitive Impairment and very early Alzheimer's disease and to tailor therapies to delay Alzheimer's onset.

Texas' investment in Alzheimer's research is positioning the Consortium at the leading edge of finding new ways to delay and ultimately prevent this mind-robbing disease. For the many of us whose family and friends have been touched by Alzheimer's, the breakthroughs cannot come soon enough.

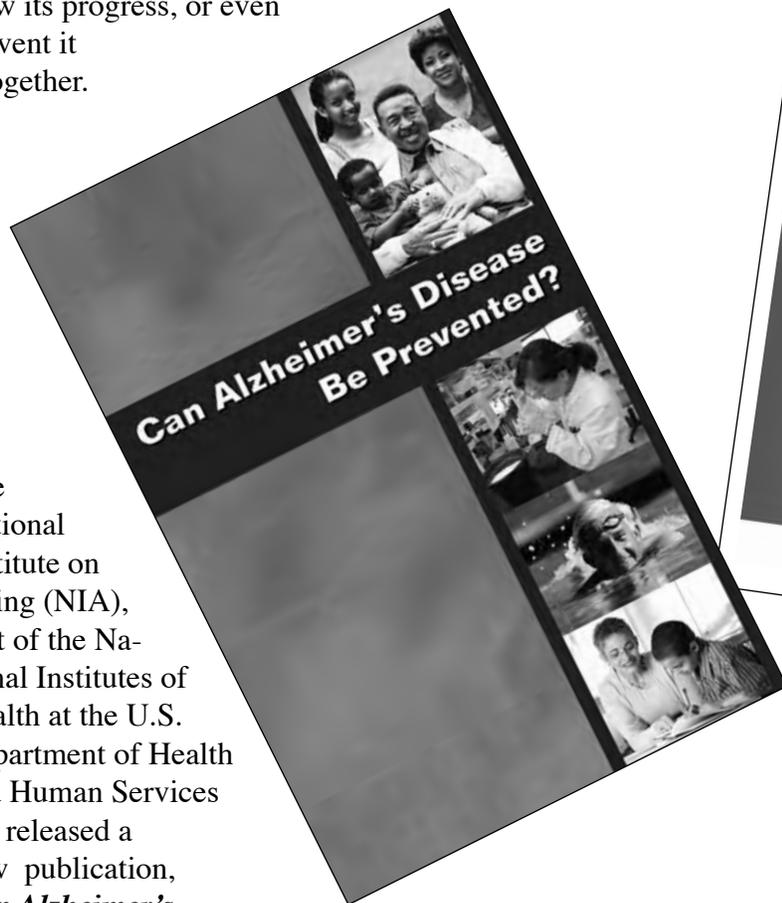


# NEW PUBLICATIONS

## Can Alzheimer's Disease Be Prevented?

Many people today are concerned with staying healthy, eating right, and keeping fit. Along with keeping their bodies healthy, they want to keep their minds sharp — and they want to avoid brain diseases, such as Alzheimer's disease (AD), that occur more often in older people.

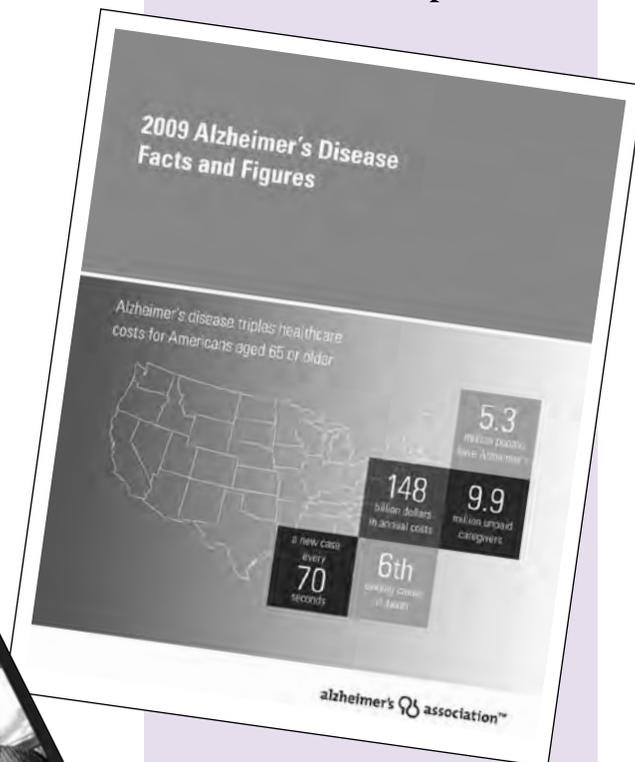
Currently, there is no known cure for AD, but recent research is raising hopes that someday it might be possible to delay the onset of AD, slow its progress, or even prevent it altogether.



The National Institute on Aging (NIA), part of the National Institutes of Health at the U.S. Department of Health and Human Services has released a new publication, ***Can Alzheimer's Disease Be Prevented?***

To view this document, to order, or to download a copy, please visit <http://www.nia.nih.gov/Alzheimers/Publications/ADPrevented/>.

The 2009  
*Alzheimer's  
Disease  
Facts and Figures*  
conveys  
the growing  
prevalence of  
AD and its impact.



To view this document, to order, or to download a copy please visit [http://www.alz.org/national/documents/report\\_alzfactsfigures2009.pdf](http://www.alz.org/national/documents/report_alzfactsfigures2009.pdf)

# Alzheimer's Study Group Final Recommendations

The national Alzheimer's Study Group, co-chaired by former U.S. House Speaker Newt Gingrich and former U.S. Senator Bob Kerrey, recently released the *National Alzheimer's Strategic Plan*.

The Alzheimer's Study Group was commissioned to assess the current efforts in combating Alzheimer's disease and to recommend strategies that will help America overcome the mounting AD crisis. Many of the plan's recommendations pillar

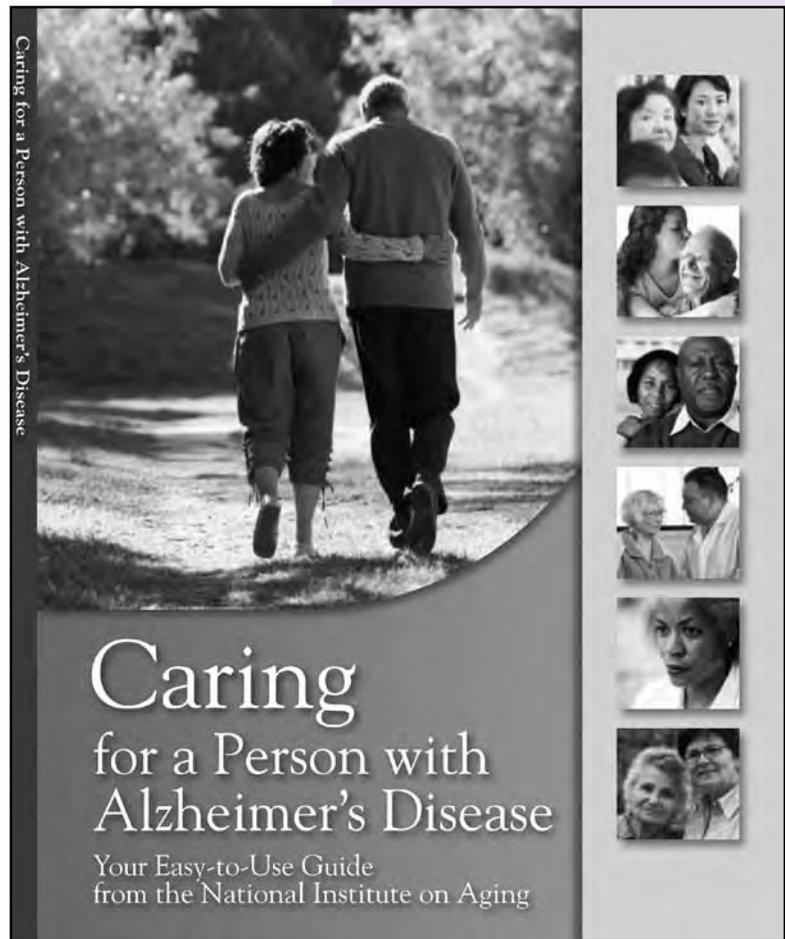
what is already happening through the Texas Alzheimer's Research Consortium — including encouraging the development of biomarkers for use in Alzheimer's clinical trials and other applications; increasing the participation of volunteers in population-based longitudinal studies; and data sharing.

## A National Alzheimer's Strategic Plan:

THE REPORT OF THE ALZHEIMER'S STUDY GROUP

To view this report, visit [http://www.pioneernet-work.net/Data/Documents/NewPressRelease/National\\_Alzheimers\\_Strategic\\_Plan.pdf](http://www.pioneernet-work.net/Data/Documents/NewPressRelease/National_Alzheimers_Strategic_Plan.pdf)

## **Caring for a Person with Alzheimer's Disease** Your Easy-to-Use Guide from the National Institute on Aging



Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging, is an easy to read handbook that is now available at no cost from the National Institute on Aging.

This handbook is designed to help family members and others understand and cope with the many challenges of caring for a person with AD.

To view, download, or order your copy  
of this resource, please visit  
<http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/>

# ATTENTION READERS



This is the last  
hard copy version of the  
*Texas Alzheimer's News*.

The newsletter will now be in  
electronic format and posted and  
available for downloading at the  
Department of State Health Services,  
Alzheimer's Disease Program  
website at:  
[http://www.dshs.state.tx.us/  
alzheimers/default.shtm](http://www.dshs.state.tx.us/alzheimers/default.shtm)

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