



Winter 2001



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**

Meeting the Spiritual Needs of People with Dementia

By Leslie Hendren, R.N., M.S.N.

Spirituality encompasses the whole of a person and virtually all of us are spiritual beings and abide by certain principles. Spirituality is more extensive and inclusive than a particular organized religion.

A person's spirituality is not ended by dementia. Spiritual care is not limited to specialists. Anyone who respects and supports that person can assist with spiritual care.

A caregiver should first be aware of his/her own spirituality. Does he/she believe in God or another higher power? What part in his/her life does spirituality hold? One must be familiar and comfortable with his/her own beliefs prior to attending to another's.

Daily activities should provide cues to another individual's spirituality. Note that person's verbal and nonverbal communication. One may say, "Is God punishing me?" Another may state, "My family would be better off without me." A patient who is constantly calling for help may be afraid of being left alone or dying while asleep. Be sensitive



to those who deny feelings of sadness, depression, or anger, while displaying these emotions through nonverbal behavior.

In later stages of dementia when cues are more difficult to ascertain, the caregiver must emphasize support in the moment. Activities which do not require memory can be therapeutic. Enjoy lunch together. Window shop to admire pretty clothes, colors and objects. Listen to music. Be here now.

Reverend Walter Barbour of the United Kingdom's Spirituality Project recommends the following for those caring for individuals with dementia:

- ◆ fostering a sense of identity;
- ◆ encouraging a sense of belonging and security;
- ◆ giving and receiving affection;

- ◆ respecting the need for space, privacy and dignity;
- ◆ listening and responding, with or without words, with patience and respect;
- ◆ empowering occupation and participation;
- ◆ providing special occasions and making every day special;
- ◆ being alongside in times of unsupportable distress;
- ◆ helping to maintain faith practices and contact with faith groups; and
- ◆ welcoming and affirming the contribution which people with dementia can make to the lives of others.

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Addressing spiritual needs is a vital part of caring for the individual with dementia. Meaning, purpose and relationships add dimension to all our lives. Adding respect and support for independence and dignity will assist the individual with dementia in keeping his spirituality intact and drawing comfort from it.

Leslie Hendren is a nurse consultant with the Adult Health Program at the Texas Department of Health.

Informal Caregiving an Upward Trend

For decades, informal caregivers have been the backbone of the long-term care system in the United States. This trend is expected to continue, with paid home care being the exception rather than the rule. Increasing numbers of family, friends and neighbors are taking on the role of informal caregiver for the millions of individuals who need assistance with daily activities to remain in their homes and avoid or delay placement in a long-term care facility.

A 1997 national survey conducted by the National Alliance for Caregiving and AARP found that one in four U.S. households was involved in helping care for an individual 50 years or older. Five million American families were said to be providing informal care to a loved one with Alzheimer's disease. An infor-

mal caregiver is one who is unpaid and most often the spouse, adult child, other relative or friend of the individual receiving care. The informal caregiver typically "learns by doing," without the benefit of formal training, and often juggles other responsibilities of career and family while serving in this role.

While each caregiving experience presents its own special circumstances, the 1997 survey pointed to the unique challenges faced by those providing care for individuals with Alzheimer's disease. It is noted that Alzheimer's caregivers typically provide more help with activities of daily living, are twice as likely to report physical and emotional stress, and experience considerable financial strain. Most of the care for an individual with Alzheimer's disease is considered custodial care, and insurance policies typically do not cover it. Medicare and Medicaid provide far less than what is needed by caregivers, who may spend eight or more years caring for a loved one with Alzheimer's disease. When caregivers were asked what they needed most, responses overwhelmingly pointed to financial assistance and respite care.

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. In Fiscal year 2001, Texas received a total of \$6.1 million to assist informal caregivers in maintaining their caregiver roles.



Texas Family Caregiver Support Program

By Beth Stalvey, Ph.D.

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.

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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.

State Caregiver Coordinator:

TDoA hired a state caregiver coordinator to manage the development and coordination of caregiver services and resources statewide. The coordinator is responsible for assessing the needs across the state in the areas of training for caregivers and professionals, technical assistance for service providers, and resource materials development. The coordinator plays a vital role in networking and sustaining partnerships

with other state agencies involved in caregiver issues. Most recently, the coordinator convened an AAA task force to work toward expanding respite services across Texas.

Capacity Building Grants:

TDoA has recently awarded a total of nine grants to communities seeking to enhance the infrastructure of caregivers services and support. Specifically, these grants assist communities in increasing their capacity to provide resources that support informal caregivers through information, access and assistance, individual counseling and support groups, decision-making, respite, and other supplemental services. The El Paso Chapter of the Alzheimer's Association was awarded one of the nine capacity building grants.

Research and Planning:

TDoA's Division on Research, Policy and Planning also plans to issue a request for proposals for special studies on caregivers in Texas. Research questions will focus on the prevalence of caregiving in Texas, the specific needs of care recipients, racial and ethnic differences in caregiving, differences between urban and rural caregivers, and decisions caregivers make in using community resources and services. Any governmental, public, private, non-profit and for-profit organization is eligible to apply for the research grants. Findings of the research will be used to develop a statewide research and policy agenda for Texas caregivers.

Texas Legal Services Center:

The Texas Legal Services Center (TLSC) has received additional support from TDoA to provide training and consultation regarding legal matters for individual caregivers and AAA benefits counselors in the areas of finance, guardianship, advance directives, and other caregiving issues. The Legal Hotline for Older Texans, administered through the TLSC, has expanded its capacity to respond to specific needs of informal caregivers caring for persons over 60 years of age. TLSC is also in the process of developing a series of print materials covering caregiving issues.

Public Information:

TDoA will disseminate educational materials through the media and other channels to promote awareness of resources available to Texas caregivers. Information related to the health, safety and well-being of both caregivers and care recipients will be developed in collaboration with other state agencies, including the Texas Department of Health, Texas Commission on Alcohol and Drug Abuse, and the Texas Department of Housing and Community Affairs. Components of an educational campaign will include publications in English and Spanish that list helpful, low-cost resources; a web site providing relevant information for caregivers; and media outreach to state leaders and the general public about caregiver needs. Also planned are special events to be held in collaboration with private-sector sponsors that link family

Best Practices



Texas Tech Breaks New Ground with First Teaching Care Center

Texas Tech University Health Sciences Center is the site for the first “teaching nursing home” in the United States. Slated for completion this spring, the Mildred and Shirley L. Garrison Geriatric Education and Care Center, combines an innovative approach to long-term care with the educational mission of a major university medical center. The Garrison Center is modeled after the traditional teaching hospital in combining these previously separated health care missions in long-term care. The center will be located on the Texas Tech campus, directly contiguous to the Health Sciences Center itself. It will provide long-term geriatric care for 120 residents, half of whom will have Alzheimer’s disease, and half will be suffering from a mix of other

age related impairments requiring skilled nursing care.

The center is part of the University’s Institute for Healthy Aging, a strategic initiative established to address the needs of the state’s rapidly growing aging population. It has been planned and developed in partnership with the Sears Methodist Retirement System, which has substantial previous experience in the field of long-term care in West Texas. By providing experiential education opportunities for healthcare professionals and students, caregiver training opportunities, rural physician outreach, and a fully operational state-of-the-art long-term care facility, the center seeks to provide an innovative model of excellence in geriatric healthcare.

The 66,000 square foot building will house classrooms, large examination rooms and conference facilities, and will utilize telemedicine and distance learning technology to enhance access for rural communities. A variety of structural innovations have been incorporated into the design of the Garrison Center, including special provisions for privacy, broad access to common living areas and activity rooms, and easy access to outdoor areas for residents who benefit from walking. The Garrison Center is the first phase of a proposed 42 acre retirement village to be located at Texas Tech’s Lubbock campus.

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caregivers with public and private support-service providers.

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. To contact your local AAA, call 1-800-252-9240.

Beth Stalvey is a research analyst at the Texas Department on Aging. For more information on statewide caregiver resources and services, visit the TDoA’s web site at www.tdoa.state.tx.us.



Family Caregiver Alliance

690 Market Street, Suite 600
San Francisco, CA 94104
1-415-434-3388
www.caregiver.org

The Family Caregiver Alliance web site features monthly interviews with leaders in various fields of caregiving, including clinical practice, research, law, ethics, and public policy. Also included are news releases, research findings and trends, information and statistics on specific cognitive disorders, and a quarterly newsletter. Site also tracks key legislative issues of concern to family caregivers.

Texas Legal Services Center

815 Brazos, Suite 1100
Austin, TX 78701
1-800-622-2520

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www.tlsc.org

The Texas Legal Services Center web site includes a directory of Texas legal resources, a referral directory for low income Texans, a listing of National Advocacy organizations, and information on the Nursing Home Advocacy Project. The Legal Hotline for Older Texans page offers online publications about supplemental social security income, Medicaid, free

and low-cost prescription drugs, and various legal documents (e.g., durable power of attorney, guardianship, living trust).

www.caregiversguide.com/guide.html

This web site offers a listing of Texas State Agencies and community resources for aging.

www.familycareamerica.com

Just type in your zip code and receive easy access to local

community resources – care facilities, financial planners, home care, hospice, home modification services, and care management. Also includes planning and assessment checklists and forms to assist caregivers with decision-making regarding record keeping and legal matters, finance, insurance, housing, self-care, and end of life issues. It includes a comprehensive glossary of caregiving terms. ■

Alzheimer's Association Chapters and Offices in Texas

<u>Chapter/Office</u>	<u>Phone Number</u>	<u>Chapter/Office</u>	<u>Phone Number</u>
El Paso Chapter 4400 North Mesa, Suite 9 El Paso, TX 79902 http://www.alzelpaso.org	1-877-544-1799 1-915-544-1799	Fort Bend Regional Office 10435 Greenbough Drive Stafford, TX 77477	1-800-266-8744 1-281-261-1871
Greater Austin Chapter 3420 Executive Center Drive, Suite 301 Livingston Building Austin, TX 78731 http://www.alz-austin.org	1-800-367-2132 1-512-241-0420	North Central Texas Chapter Fort Worth Region One Summit Avenue, Suite 300 Fort Worth, TX 76102 http://www.alz.org/tarrant	1-800-471-4422 1-817-336-4949
Greater Dallas Chapter 7610 North Stemmons Dallas, TX 75247 http://www.alzdallas.org/	1-800-515-8201 1-214-827-0062	Abilene Region PO Box 3344 Abilene, TX 79604	1-888-511-4132 1-915-672-2907
Greater East Texas Chapter PO Box 630636 Nacogdoches, TX 75963	1-800-246-7888 1-936-569-1325	Arlington Office Arlington Human Service Center 401 W. Sanford, Suite 200 Arlington, TX 76011	1-817-460-7001
Greater Texarkana Area Chapter 4082 Summerhill Square Texarkana, TX 75505	1-877-312-8536 1-903-792-6122	Wichita Falls Region PO Box 3008 Wichita Falls, TX 76301	1-940-767-8800
Greater West Texas Chapter 4400 N. Big Spring #C-32 Midland, TX 79705	1-800-682-1174 1-915-570-9191	Northeast Texas Chapter 3613 South Broadway, Suite 401 Tyler, TX 75701 http://www.netxalz.org	1-800-789-0508 1-903-509-8323
Houston and Southeast Texas Chapter 11251 Northwest Freeway, Suite 300 Houston, TX 77092 http://www.alztex.org	1-800-266-8744 1-713-266-6400	Panhandle Chapter 2200 West Seventh Amarillo, TX 79109 alz@nts-online.net	1-800-687-8693 1-806-372-8693
Beaumont Regional Office 780 South Fourth Street Beaumont, TX 77001	1-800-449-1613 1-409-833-1613	Rio Grande Valley Chapter 902 Morgan Blvd., Suite 2 Harlingen, TX 78550	1-800-523-2007 1-956-440-0636
Brazos Valley Regional Office 1605 Rock Prairie Road, #214A College Station, TX 77845	1-800-967-8015 1-979-680-8888	South Central Texas Chapter 7400 Louis Pasteur, Suite 200 San Antonio, TX 78229 http://www.sctx-alzheimers.org	1-800-523-2007 1-210-822-6449



Alzheimer's Care: Making a Difference in Everyday Life

The Texas Council on Alzheimer's Disease and Related Disorders proudly presents their biennial conference offering the latest in diagnosis, treatment and care of individuals with Alzheimer's disease and related disorders

If you are a physician, nursing facility administrator, assisted living manager, activity director, nurse, case manager, counselor, home health aide, ombudsmen, legislator or family caregiver, you won't want to miss this comprehensive, cutting-edge conference!

**SAVE THESE DATES:
June 6 and 7, 2002 DoubleTree Hotel, Austin**

Topics:

- Advances in diagnosis and treatment
- Latest in genetic research
- Activity planning at home and in long-term care facilities
- Dementia care mapping
- Innovative therapies
- Behavioral agitation
- Addressing special healthcare needs of individuals with Alzheimer's disease
- Accessing respite care options
- Healthy caregiving

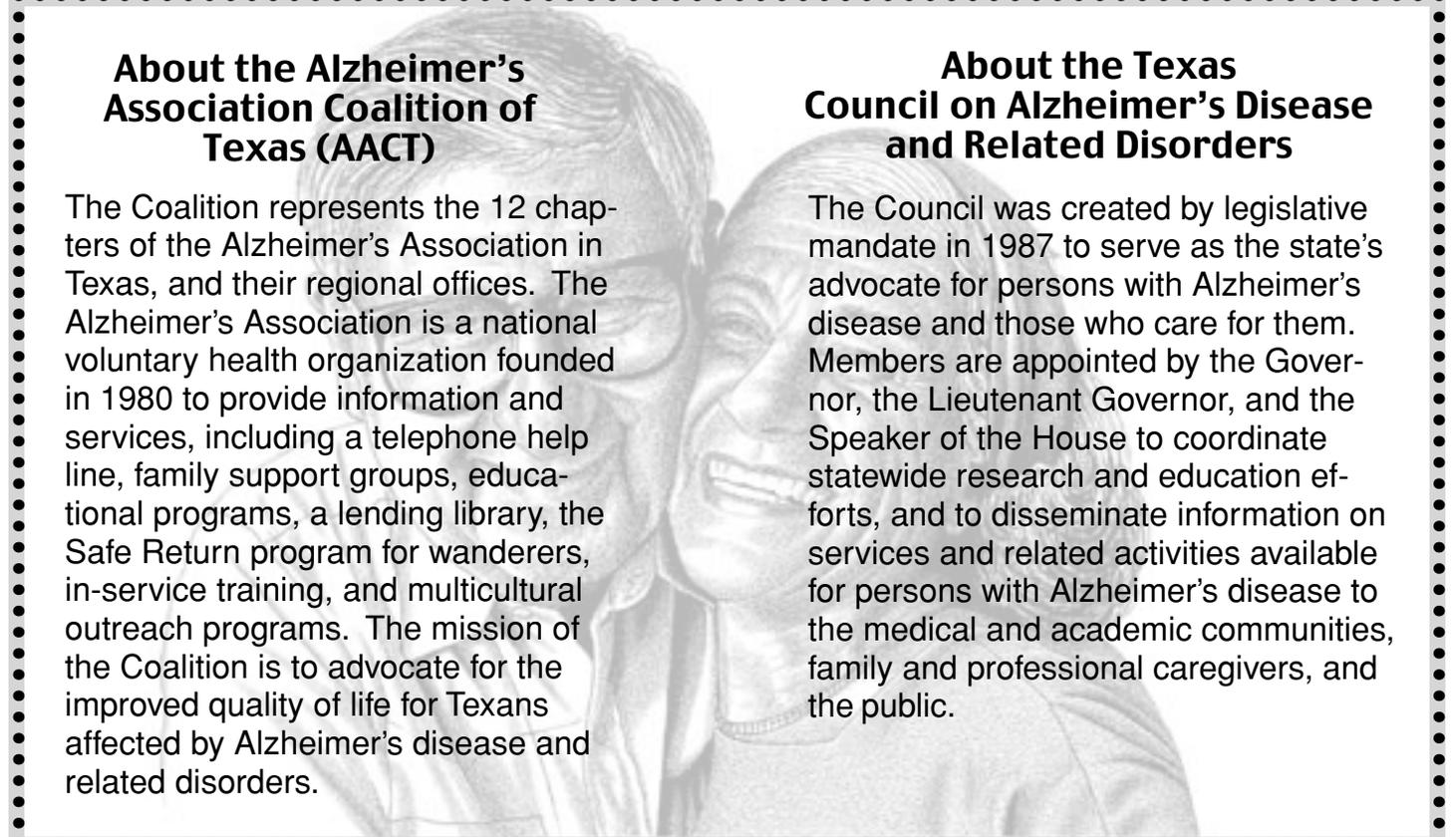
Featured speakers:

- Rachelle Smith Doody, M.D., Ph.D., Baylor College of Medicine
- Roger N. Rosenberg, M.D., UT Southwestern School of Medicine
- Ronald C. Peterson, M.D., Ph.D., Mayo Clinic
- And numerous other experts in the treatment and care of individuals with Alzheimer's disease
- Continuing education for multiple disciplines will be available
- Be sure to check your mail for the conference registration brochure in the months to come.

The registration brochure will also be available to download from our web site:
www.tdh.state.tx.us/osp/alz.htm.

For now, please save these dates: June 6 and 7, 2002!





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

The Coalition represents the 12 chapters 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.

**Texas Alzheimer's News is published by:
Texas Department of Health
Adult Health Program
1100 West 49th Street
Austin, Texas 78756-3199**

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1-800-242-3399 or 1-512-458-7534

For more information on Alzheimer's disease, to be placed on the newsletter mailing list, or to change your mailing address, please call 1-800-242-3399. There is no cost to subscribe. Newsletters are also posted on the Internet at www.tdh.state.tx.us/osp/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.

ANNOUNCING!
**8th International
Conference on
Alzheimer's Disease
and
Related Disorders
July 20-25, 2002
Stockholm, Sweden**

For complete program information and where and when to submit abstracts, call the Alzheimer's Association at (312) 335-5813 or email the Association at internationalconference@alz.org.

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Adult Health Program
1100 West 49th Street
Austin, Texas 78756-3199**

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PAID
Permit No. 28
Austin, Texas



Publication
#42-10500