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Alzheimer's News



Someone to Stand by You



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

Government Publications
Texas State Documents

When Our Parents Become Our Children

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By Brenda Avadian, M.A.

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What if you became your parent's parent? What would it be like to be your mother's parent? What would you do if your father tried to shoplift?

In September 1996, my husband, David and I had moved my father from his Wisconsin home of 45 years into our California home. In early 1997, while my 87-year old father and I were shopping at a local department store, he spotted a wallet misplaced in the candy aisle. He said, "Hey, a wallet! I'll look at it later," and he discretely placed it in his pocket. I smiled and thought he was being cute. But he refused to put it back. I feared he might be arrested, handcuffed, and taken to jail for shoplifting. Then I imagined him in a panic wondering what had happened and why these people were restraining him. I would be helpless once the law stepped in. My father, a man who had never committed a crime, would be traumatized. He wouldn't understand why he was in jail.

Anticipating these consequences, I asked, "Mardig," (we called him by his first name, Mardig which is Armenian for Martin), "is that yours?" "Shoosh," he said sternly, placing his index finger to his lips. I grew more serious, "No, Mardig,

is that wallet yours?" "Well, it's not theirs!" he exclaimed. "Because if it was, they would know where to place it," he reasoned.

I was perplexed. How do I get an adult, *my father*, to listen to me? "Please Mardig, take that wallet out of your pocket, now!" I insisted firmly in a low tone of voice. I didn't want to get him riled up. "No!" he said and began walking ahead of me. "Mardig," I caught up to him and pulled his left arm as his left hand held the wallet in his pocket, "Please, you must give me that wallet. You can get arrested for stealing. You can go to jail!" "Well, no one will know about it if you keep your voice down," he said. Finally, I pulled his arm out of his pocket and reached in his left pocket and removed the wallet to his loud objections.

As I stood in that department store irritated at my father's behavior, I feared what others might perceive as a younger adult accosting an older man and stealing his wallet. Yet, just as a responsible parent ensures his/her child follows the rules, I too had to make sure my father followed the law. The only difference is, a parent can teach his/her child what is right. Over time, the child will learn. *My child*, my father, could

no longer learn because Alzheimer's disease is destroying his brain. This terminal disease—his death sentence—is taking my father away, piece-by-piece, from those he loves and from those who love him. My father cannot care for himself. He needs help with all the basic functions of life many of us take for granted—toileting, dressing, showering, and now even eating. He no longer knows who I am as I feed him. Sometimes he doesn't even know how to swallow his food.

According to the National Family Caregivers Association (NFCA), there were 54 million caregivers in America who provided care for an elderly, disabled, or chronically ill friend or relative during the past year. More than half of these caregivers are between 35 and 64 years old. Providing care for a family member during key wage-earning years places a huge financial toll on their families. Beyond the economic burden, there is stress on the caregiver. It is estimated that 50 percent of caregivers suffer from depression due to the demands of caregiving.

No matter whom we care for, here are a few survival tips for caregivers adapted from the "Ten

Continued on page 2

Suggestions" in "Where's my shoes?" My Father's Walk Through Alzheimer's.

1. **Recognize and accept that you cannot do it all by yourself.** Try to define your limits and then enlist the help of family members, friends and organizations who can help you when you are stretched beyond those limits. Early on (and only after we were able to accept the idea) we took my father to the local Adult Day Care. This afforded him quality care and socialization opportunities. We even learned that he loved to dance — and he danced with the ladies, some ten and twenty years his junior, until he tired them out!
2. **Join a support group.** These are groups of 5, 10, or even 20 people who are taking your journey (Alzheimer's/dementia; Multiple Sclerosis; bereavement; stroke, Parkinson's). They may meet weekly or monthly. I thought I was much too intelligent and busy to make time for a support group. Yet I had a lot of questions, which the Administrator of the local Adult Day Care stopped answering because she wanted me to attend a support group. That was the best thing she did for me. I have been attending since late October 1996 and these members have become my *LIFE*-support group!
3. **Take time for yourself.** Whether it is an hour, a day, or a week, if you don't take a little time to replenish yourself, you will be unable to have the strength or health to care for your loved one. Sadly, I have seen caregivers pass on first and then their loved ones' care

is left to the state or other family members and friends. There are no heroes among caregiver martyrs.

4. **Seek appropriate professional advice (medical, legal, financial).** Do this early, especially with dementia-related illnesses. Once the person loses his/her ability to make decisions, the state will take control if prior arrangements have not been made.
5. **Treat your loved one with dignity.** Approach him/her gently. Establish and maintain eye contact while speaking and listening to your loved one. Realize that you could be in your loved one's shoes and the recipient of *your* care.

Today, my father lives in a skilled nursing facility. After the intense and around-the-clock caregiving for one with Alzheimer's, David and I were not getting enough sleep and started to believe *we were getting Alzheimer's just trying to keep up with my father's care!* Placing him was the most emotionally difficult decision we made. Yet today he is thriving at age 90. Although he does not know me, and he uses a wheelchair most of the time, I visit him for a couple of hours once or twice a week. I help feed him and accept what the disease hasn't taken from my father during these times we share together.

The bittersweet joys are what we caregivers learn to accept. As we slowly lose our loved ones the joys get simpler and smaller, like feeding my father his dinner.

Brenda Avadian, M.A. is an author and professional speaker. Known as "The Caregiver's Voice", she speaks nationally on caregiving issues and is the author of five

books including "Where's my shoes?" *My Father's Walk Through Alzheimer's* plus the forthcoming titles, *Caregiving 101* and *Finding the JOY in Alzheimer's: Caregivers Share the JOYFUL times*. You are welcome to email her directly at CAREVOICE@aol.com.



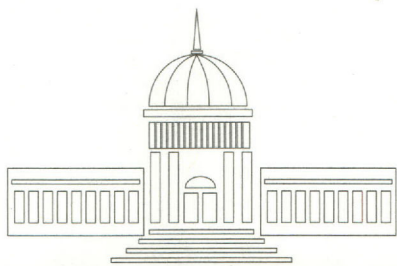
<http://www.elderoptionsof.texas.com>

The Elder Options of Texas Web site features numerous links to caregiver resources in cities throughout Texas, articles about senior housing and care options, an annotated list of books on topics including Alzheimer's disease, children of aging parents, long term care, hospice care, and caregiver resources, and a community calendar of events for Central Texas.

<http://www.texseniorlaw.com/>
Texas Senior Law includes current articles regarding senior issues, a monthly newsletter, a senior sounding board where consumers can ask questions, free estate planning forms, and Texas senior law links.

<http://www.elderlawanswers.com/>

Elder Law Answers includes information on estate planning, disability planning, long-term care insurance, medical directives, nursing home issues, Medicaid, Medicare, Social Security, and state specific articles.



Outcomes of the 77th Texas Legislative Session

The 77th session of the Texas Legislature adjourned on May 28 with 1,100 of 5,600 bills filed and sent to the Governor, who then had 30 days to either veto or sign them into law. Following is legislation tracked by the Alzheimer's Association Coalition of Texas. Under each topic, we begin with the objective advocated by members and other stakeholders, followed by the outcome.

Community Alzheimer's Resources and Education (CARE) Program

To maintain funding at least at the current levels for the CARE program with the future objective of establishing at least one CARE site in each Texas Department of Human Services (TDHS) region of the state.

Rider 28 to the state budget reads "It is the intent of the Legislature that out of amounts appropriated to Strategy A.1.3, Long Term Care Eligibility and Service Planning, the Department of Human Services shall allocate \$1,523,520 in fiscal year 2002 and \$1,523,520 in fiscal year 2003 for the CARE program." This represents an increase of \$609,000 over the last biennium, a significant accomplishment in a year of budget shortfalls. Monies will be used for programs and services at the eight existing CARE sites.

Medicaid Reimbursement Rate

To increase the Medicaid reimbursement rate for nursing facilities to improve the quality of care by increasing wages and benefits for staff as well as providing appropriate training.

Tile Index for Level of Effort (TILE)

To require TDHS to review and revise the TILE to better account for the varying resource needs of nursing home residents with Alzheimer's disease.

HB 1001, co-authored by Naishtat and Wohlgemuth and sponsored by Zaffirini, supported both the Medicaid reimbursement and TILE objectives. However, on June 18 the Governor vetoed this legislation. Listed below are key objectives of the bill which the Coalition will continue to pursue.

- ★ Evaluate the current methodology used to determine Medicaid reimbursement rates for nursing facilities to accurately reflect all justifiably reimbursable costs of doing business.
- ★ Evaluate the TILE classification system used to quantify the intensity of the care needs of individuals in nursing facilities. Specifically, review the TILE system to determine whether it accurately accounts for the care needs of people with dementia, including individuals with Alzheimer's disease.
- ★ In evaluating TILE, seek the input of relevant professionals and other individuals or organizations with expertise in caring for people with dementia, including Alzheimer's disease.

SB 1839, sponsored by Montcrief, pertains to liability insurance rates for long-term care facilities. The portion of concern to Alzheimer's caregivers, sometimes referred to as the Granny Tax or the Bed Tax, has been removed. For-profit and not-for-profit nursing homes will not be subject to these fees. Instead fees will be collected from community mental health and mental retardation centers. These funds are to be used to draw down additional Federal funds. However, all Texas nursing homes are required to carry a minimum of \$1 million per occurrence in liability insurance beginning in September 2003.

Community Based Alternatives Program

To increase funding for the Community Based Alternatives Program.

Long Term Care funding was provided to increase the number of community care slots in both the CBA and CLASS programs during the next biennium. Current estimates are that 2,675 slots will be available in the CBA program.

Safe Return

To obtain passage of a resolution establishing a statewide Safe Return Alert, recommending that the media use this method to alert communities of missing persons with Alzheimer's disease and related dementia.

HR 560, introduced by Brimer and SR 496, introduced by Armbrister, recognizes the humanitarian work of Safe Return and encourages radio and television stations in Texas to implement a plan to help Safe Return find missing Alzheimer's individuals.

Best Practices

Advanced Planning Essential for Alzheimer's Patient

Everyone should devote time to planning for the future, such as establishing a will or estate plan to ensure that their wishes are carried out as they intended. For a person with Alzheimer's disease, advance planning is essential to fulfilling end-of-life wishes. Individuals with Alzheimer's may have the capacity to manage their own legal affairs right now, but as the disease progresses, they will need to rely on others to act in their best interest.

Advance planning protects an individual's right to make his or her own health care and financial choices and prevents unnecessary suffering for families who may struggle with these decisions later on. It is a proactive process that enables the individual to make decisions about their future, along with family members, health care providers and counsel, prior to their physical and cognitive decline.

There are certain documents and relationships that must be put into place to assure the future needs and desires of the Alzheimer's patient are executed. An **advance directive** is any statement made by a competent individual about preferences for future medical treatment in the event that the patient is unable to make decisions at the time of treatment. The two most common forms of advance directives are the Directive to Physicians and the Medical Power of Attorney.

The Directive to Physicians and Family or Surrogates (formerly called the Living Will) is a written statement of wishes regarding the

use, withholding or withdrawal of life-prolonging treatment, nutrition and hydration if a person has a terminal condition and is incapable of making decisions for himself at that time. This document will usually state that the signer's life should not be artificially prolonged by extraordinary measures when there is no reasonable expectation of recovery from extreme physical or mental disability. However, the document can request that every effort be made to prolong life by extraordinary measures. Generally, this directive only goes into effect if the person is no longer able to make his own decisions.

A power of attorney gives an individual (principal) the opportunity to designate a surrogate (agent), usually a trusted family member or friend, to legally make decisions when he is no longer capable. Most powers of attorney are "durable," meaning that they are valid even after the principal is no longer competent.

The **Medical Power of Attorney** (formerly called the durable power of attorney for health care) allows the agent to make health care decisions in the event that the principal becomes incapable of making informed decisions. It also allows the principal to provide the agent, family members and health care providers with written instructions regarding the kind of treatments that should or should not be given. Even with the Medical Power of Attorney in place, the individual will continue to make his own medical decisions as long as he is capable of doing so and can communicate those decisions. The agent's authority starts only when the attending physician certifies in writing that the individual



no longer has the capacity to make those decisions. Further, a power of attorney can be changed or revoked at any time and does not give the agent authority to override the decision-making of the principal. For the Alzheimer's patient, this means that he retains the right to make his own decisions as long as he is competent.

There are similar legal documents and processes available to ensure the principal's financial matters are handled according to his wishes.

A Texas **Durable Power of Attorney** authorizes an agent to manage and make decisions regarding the income and assets of the principal. The agent is responsible for acting according to the instructions and in the best interest of the principal.

A **Revokable Trust** is another way to ensure the management of property. In this case, a trustee is appointed to invest and manage an individual's trust assets in the event that the individual is no longer able to manage finances because of cognitive impairment.

Texas law provides that a court may appoint a guardian for a person who has become mentally or physically incapable of making personal or financial decisions. **Guardianship** is a legal relationship that gives the court-appointed guardian the duty and right to act on behalf

of the incapacitated individual to make personal, legal and financial decisions. The **Declaration to Appoint Guardian** is a document designed to prevent a probate court from appointing an institutional guardian in the event of later incapacity. The Declaration to Appoint Guardian is often executed contiguously with the Medical Power of Attorney and Texas Durable Power of Attorney. In many cases, the Medical Power of Attorney serves as guardian of the person and the Texas Durable Power of Attorney serves as guardian of the estate.

Once these documents have been completed, there are a few final necessary steps to make them effective:

- ◆ The principal should discuss the advance directives with his health care provider before they are signed. The provider may suggest some additional information to include in the directives.
- ◆ Each document listed above has certain signature and witness requirements. The Medical Power of Attorney, Texas Durable Power of Attorney, and the Declaration to Appoint Guardian must be notarized.
- ◆ A copy of the signed Directive to Physicians should be given to the individual's doctor and hospital.
- ◆ A copy of the signed Medical Power of Attorney and Texas Durable Power of Attorney should be given to the respective agents.
- ◆ A copy of all signed documents should be stored in a safe place, given to family members and significant others and retained by one's attorney.

Planning ahead is essential for the Alzheimer's patient. It gives the individual a voice in decisions about future medical care and estate planning.

Memory Walk Events Across the State

Alzheimer's Association Chapters across the state are gearing up for Memory Walk 2001. Last year thousands of individuals participated in Memory Walks across the state and the nation, helping to raise funds for vital research and community services. Events planned in Texas include:

El Paso Chapter

7th Annual Memory Walk ► El Paso
Saturday, September 22 @ Sunland Park Racetrack
Frank Lopez (915) 544-1799

Greater Austin Chapter

10th Annual Greater Austin Memory Walk ► Austin
Saturday, October 13 @ Auditorium Shores
Amy Matta (512) 454-5476

1st Annual Heart of Texas Memory Walk ► Temple
Saturday, September 15 in Downtown Temple
Amy Matta (512) 454-5476

2nd Annual Hill Country Memory Walk ► Marble Falls
Date and location to be announced
Amy Matta (512) 454-5476

Greater East Texas Chapter

Memory Walk & East Texas Poultry Festival ► Center
Saturday, October 6 on the Square
Robin Dawley (936) 569-1325

Memory Walk ► Lufkin
Saturday, October 20 @ Anderson Elementary School
Robin Dawley (936) 569-1325

Memory Walk ► Nacogdoches
Saturday, October 20 @ TJR Middle School
Robin Dawley (936) 569-1325

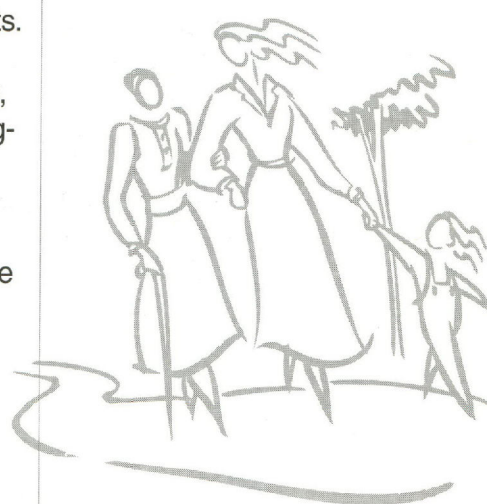
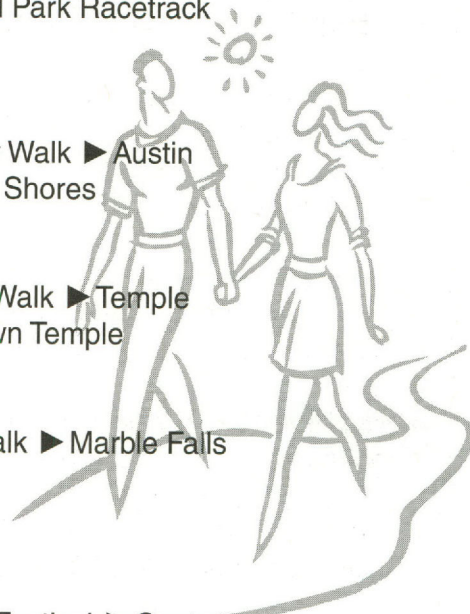
Memory Walk ► Livingston
Saturday, October 27
@ High School Stadium
Robin Dawley (936) 569-1325

Greater Texarkana Area Chapter

Memory Walk ► Texarkana
Saturday, September 29
@ Spring Lake Park
Melba Phillips (903) 792-6122

Greater West Texas Chapter

Memory Walk ► Midland/Odessa
Saturday, October 13 @ Symphony Building, Midland International Airport
Polly Welmaker (915) 570-9191



Memory Walk Events Across the State... *continued*

Memory Walk ► Big Spring
Saturday, October 13 @ Belaski Pavilion
Polly Welmaker (915) 570-9191

Memory Walk ► San Angelo
Saturday, October 13 —
location to be announced
Tricia Shelton (915) 653-1724

Memory Walk ► Andrews
Saturday, October 20 @ City Park
Polly Welmaker (915) 570-9191

Houston & Southeast Texas Chapter

Beaumont Area Memory Walk ► Beaumont
Saturday, September 22 @ Babe
Didrickson Zaharias Memorial Park
Colleen Grimes (409) 833-1613

Brazos Valley Area Memory Walk
► College Station
Saturday, October 13 @ Cinemark
Hollywood USA Theatres
Carla Graham (979) 774-4653

Houston Area Memory Walk ► Houston
Saturday, October 27 @ AMC Theatres
in Sugar Land
Lisa Bartkowiak (713) 266-6400

Northeast Texas Chapter

Paint the Town Purple Annual Memory
Walk ► Tyler
Thursday, October 4, 6:00 p.m.
@ Rose Rudman Trail
Glenda Lauter (903) 509-8323

Paint the Town Purple Annual Memory
Walks ► Longview, Marshall, Mineola
Dates and locations to be announced
Glenda Lauter (903) 509-8323

South Central Texas Chapter

10th Annual Memory Walk ► San Antonio
Saturday, September 22
@ Retama Race Track
Ginny Funk (210) 822-6449

2nd Annual Memory Walk ► Kerrville
Saturday, October 6 @ VA Hospital
Victor Argilagos (830) 896-1244

2nd Annual Memory Walk ► New Braunfels
Saturday, October 20 @ Landa Park
Ginny Funk (210) 822-6449

1st Annual Memory Walk ► Pleasanton
Saturday, October 6 @ the City Park
Ginny Funk (210) 822-6449

1st Annual Memory Walk ► Corpus Christi
Saturday, October 13 – location to
be announced
Ginny Funk (210) 822-6449

Tarrant County Chapter

Memory Walk on the Brazos ► Weatherford
Saturday, September 22 @ Silverado Ranch
Theresa Hocker (817) 336-4949

Memory Walk on the Trinity ► Fort Worth
Saturday, September 29
@ Trinity Park Bike Trail
Theresa Hocker (817) 336-4949

Panhandle Area Chapter

2001 Memory Walk ► Amarillo
Sunday, October 7 @ Sam Houston Park
Cheryl Watson (806) 372-8693

West Central Texas Chapter

10th Annual Memory Walk ► Abilene
Saturday, September 22 @ Nelson Park
Sue Davis (915) 672-2907

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

The Coalition represents the 14 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 state-wide 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 <http://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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