



Winter 2003



# 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

## Holidays and Alzheimer's

### Alzheimer's Association

For most families, holidays are filled with opportunities for togetherness, sharing, laughter, and memories. But holidays can also be filled with stress, disappointment, and sadness.

Because of the changes he or she has experienced, the person with Alzheimer's may feel a special sense of loss during the holidays. At the same time, caregivers may feel overwhelmed maintaining holiday traditions while caring for the person with this disease. In addition, caregivers may feel hesitant to invite family and friends over to share the holiday, for fear they will be uncomfortable with behavior changes in the family member.

If you're feeling guilty, angry, or frustrated before, during, or after holiday celebrations, it may help to know that these feelings are normal and that you're not alone. Here are some suggestions that may help to ease the burden of caregiving and make holidays happy, memorable occasions.

#### ACTION STEPS

#### **Adjust expectations.**

■ Discuss holiday celebrations with relatives and close friends. Call a face-to-face meeting or arrange for a long distance telephone conference call to discuss major holiday celebrations. Make sure that family members understand the situation and have realistic expectations. By discussing past celebrations, you may be able to agree on how you'll handle upcoming holidays.

■ Give yourself permission to do only what you can reasonably manage. No one can expect you to maintain every holiday tradition or event. If you've always invited 15-20 people to your home, consider inviting five for a simple meal. Also consider asking others to bring dishes for a potluck meal or to host the meal at their home.

■ Familiarize others with your situation by writing a letter that

makes these points:

"I'm writing this letter to let you know how things are going at our house. While we're looking forward to your visit, we thought it might be helpful if you understood our current situation before you arrive.

"You may notice that \_\_\_ has changed since you last saw him/her. Among the changes you may notice are \_\_\_. I've enclosed a picture so you know how \_\_\_ looks now.

"Because \_\_\_ sometimes has problems remembering and thinking clearly, his/her behavior is a little unpredictable. Please

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understand that \_\_\_ may not remember who you are and may confuse you with someone else. Please don't feel offended by this. He/she appreciates your being with us and so do I. Please treat \_\_\_ as you would any person. A warm smile and a gentle touch on \_\_\_'s shoulder or hand will be appreciated more than you know.

"I would ask that you call before you come to visit or when you're nearby so we can prepare for your arrival. Caregiving is a tough job, and I'm doing the very best I can. With your help and support, we can create a holiday memory that we'll treasure."

### ***Involve the person with Alzheimer's disease.***

- Throughout all stages of preparation, involve the person in safe, manageable activities. This can help to prepare the person for the holiday and give you an opportunity to spend quality time together. You may want to begin slowly by asking the person to help you prepare food, wrap packages, hand decorations, or set the table. (Avoid using candies, artificial fruits/vegetables, or other edibles as decorations. Blinking lights may confuse the person.)

- Maintain the person's normal routine so that holiday preparations don't become disruptive or confusing. Remember: Taking on too many tasks at one time can wear on



you and the person.

- Build on past traditions and memories. Your family member may find comfort in singing old holiday songs, for example. But also experiment with new holiday traditions, such as renting seasonal videos.

### ***Adapt gift giving.***

- Encourage people to buy useful gifts for the person such as an identification bracelet (available through the Safe Return Program), comfortable, easy-to-remove clothing, audiotapes of favorite music, videos of family members, and photo albums.

- Warn people about difficult or unsafe gifts. Advise people not to bring dangerous tools or instruments, utensils, challenging board games, complicated electronic equipment, or pets.

- Allow the person to join in giving gifts. For example, someone who once enjoyed cooking may enjoy baking cookies and packing them in

tins or boxes. Or, you may want to buy the gift and allow the person to wrap it.

- Don't neglect your own needs. If friends or family members ask what you want for a gift, suggest a gift certificate to a restaurant, laundry or dry cleaner, or cleaning service. If you don't receive these gifts, celebrate the holiday by giving such a gift to yourself.

- Ask for help and support. Develop a bulletin board for listing tasks and responsibilities. If someone ever asks, "What can I do to help?" you can respond with a specific idea.

### ***Try to be flexible.***

- Consider celebrating over a lunch or brunch, rather than an evening meal, to work around the evening confusion or sundowning that sometimes affects some people with Alzheimer's. Also consider serving nonalcoholic drinks and keeping the room bright.

- Prepare to deal with your post-holiday letdown. You may want to arrange for in-home care so you can enjoy a movie or lunch with a friend and reduce post-holiday stress.

- Remember that holidays are opportunities to share time with the people you love. Try to make these celebrations easy on yourself and the person with Alzheimer's disease so that you may concentrate on enjoying your time together.



## Legislative Update

The Health and Human Services Commission released a Transition Plan in accordance with House Bill 2292. Goals and Vision for the transitional process include:

1. *FOCUS ON CLIENT NEEDS AND PROGRAM DELIVERY*
2. *EFFECTIVE STEWARDSHIP OF PUBLIC RESOURCES*
3. *CULTURAL CHANGE AND ACCOUNTABILITY*

In addition, the Executive Commissioner, Albert Hawkins, announced four commissioners for the new consolidated agencies. The Department of Family and Protective Services and the Department of Assistive and Rehabilitative Services will begin formal operations in January 2004, and the Department of State Health Services and the Department of Aging and Disability Services will begin formal operations in Spring/Summer 2004.

A preferred drug list for Medicaid clients is expected to be in

place by February or March of 2004. This list will include all prescription drugs approved by a committee to be used by Medicaid clients. Any drugs not included in the list will have to meet prior approval authorization. The Alzheimer's Association Coalition of Texas is asking for a category of drugs called "Alzheimer treatment drugs" to be included in the preferred drug list in order to ensure that the latest treatment drugs are available to Medicaid clients with Alzheimer's disease.

### Alzheimer's Association Encouraged by FDA Approval of Memantine

CHICAGO, Oct. 17, 2003 — The Alzheimer's Association is encouraged by today's U.S. Food and Drug Administration (FDA) approval of memantine to treat moderate to severe Alzheimer's disease.

"Today's FDA action provides additional strategies to intervene with the devastating effects of Alzheimer's disease," said William Thies, Ph.D., vice president, Medical and Scientific Affairs for the Association.

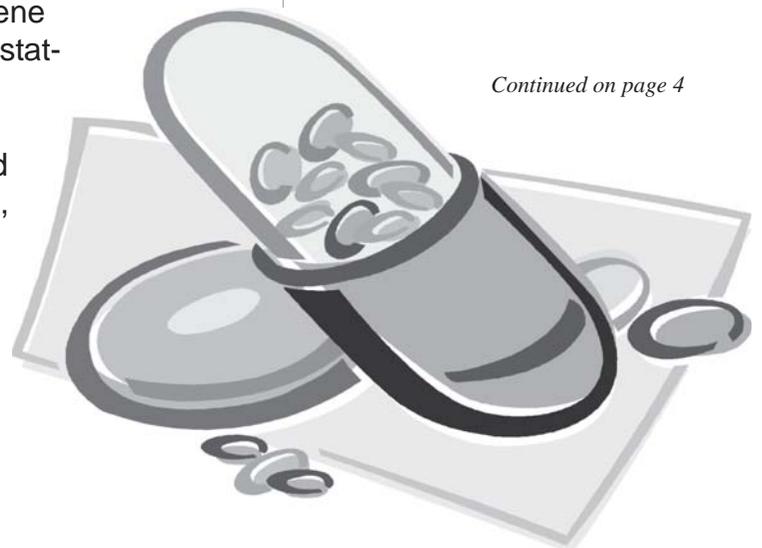
"In particular, this is the first treatment approved for those with more severe Alzheimer's disease."

The Alzheimer's Association is a strong advocate for the development of a broad spectrum of interventions for all stages of the disease.

"The Alzheimer's Association, through its research grantmaking program, has been a champion of drug development using different approaches and exploiting a variety of different mechanisms of action," Thies said.

"For patients, families and physicians, having a new approved treatment with a novel mechanism of action — as is the case with memantine — raises the possibility that the drug can be used either alone or in combination with other approved treatments. Our goal is to have multiple treatment options so that physicians can find a therapy that works safely and effectively for every person with the disease," Thies said.

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Newly published research suggests that 4.5 million Americans now have Alzheimer's disease. As the baby boom generation ages, the estimated Alzheimer prevalence is 11.3 million to 16 million by 2050.

"The discovery of effective new interventions is urgently needed to stem the tide of the pending worldwide epidemic of Alzheimer's disease, its devastation of individuals and families, and the potential bankrupting of the American healthcare system due to its costs," said Sheldon Goldberg, president and CEO of the Alzheimer's Association.

### ***The FDA's Action***

On Friday, October 17, the FDA approved memantine (brand name, Namenda®) for treatment of moderate to severe Alzheimer's disease.

Memantine is manufactured and marketed in the United States by Forest Laboratories.

### ***FDA Action Points to Need for More Federal Research Funding***

Thies pointed out that current drug treatments for Alzheimer's, including memantine, help ease some of the symptoms of the disease. Approved treatments do not yet address the underlying cause of the disease.

"America's 4.5 million people with Alzheimer's disease, their

caregivers and family members desperately need therapies that go beyond treating only the symptoms of Alzheimer's to actually slow or stop its progression and prevent its relentless destruction of brain cells," Thies said.

"The approval of another symptomatic treatment further underscores the need to increase the federal commitment to research into the cause of Alzheimer's disease, so that we can rationally develop strategies for preventing and even curing this disease," Thies added.

The Alzheimer's Association is working with Congressional leaders to increase federal funding for Alzheimer research from the estimated \$640 million the National Institutes of Health will spend in 2003 to \$1 billion annually.

### ***About Memantine***

Memantine appears to regulate the activity of glutamate, one of the brain's specialized messenger chemicals. At normal concentrations, glutamate plays an essential role in learning and memory. Imbalances in glutamate levels are thought to be one factor that may contribute to Alzheimer-related memory problems and to damage or destroy nerve cells. Because these interactions are out of balance in Alzheimer's disease and some related disorders, the drug may help maintain normal processes that promote cell health.

Memantine's action in the glutamate system differs from the activity of the four cholinesterase inhibitors that are currently approved in the U.S. for treatment of Alzheimer's disease. Cholinesterase inhibitors temporarily boost levels of acetylcholine, another messenger chemical that becomes deficient in the Alzheimer brain. These differing modes of action raise the possibility that individuals may be able to take memantine either as stand-alone therapy or in combination with cholinesterase inhibitors.

The four currently approved drugs for Alzheimer's disease all are indicated for use in patients with mild to moderate disease. Memantine is the first drug indicated for moderate to severe Alzheimer's disease.

### ***The Alzheimer's Association***

The Alzheimer's Association is the world leader in Alzheimer research and support. Having awarded more than \$150 million to nearly 1,300 projects, the Alzheimer's Association is the largest private funder of AD research in the U.S. The association's vision is a world without Alzheimer's disease. For more information about Alzheimer's disease, research and treatments, please visit [www.alz.org](http://www.alz.org) or call 800.272.3900.



### Additional information

Forest is providing prescribing information at [www.namenda.com](http://www.namenda.com) and at 1.877.2-NAMENDA (1.877.262.6363).

### Research News Story

See: [www.alz.org](http://www.alz.org) > Research News

### Forest Laboratories Press Release

See: [www.frx.com](http://www.frx.com)

### FDA Press Release

See: [www.fda.gov](http://www.fda.gov)



## THE FORGETTING

A PORTRAIT OF ALZHEIMER'S

Don't miss the PBS special, ***The Forgetting: A Portrait of Alzheimer's***, which airs on January 21, 2004 at 8 pm CST. The 90-minute documentary explores the latest Alzheimer research and the devastating toll Alzheimer's takes on people with the disease and caregivers. In examining this looming social and economic crisis, ***The Forgetting*** focuses on several families whose lives have been steadily ravaged by Alzheimer's. Like so many coping with this tragedy, these families are drawing on reservoirs of strength and compassion to stay focused on the person they love even as personalities and capabilities change from day-to-day.

A groundbreaking Web site accessible at [www.pbs.org/theforgetting](http://www.pbs.org/theforgetting) will serve as a central hub for Alzheimer's information and support, providing advice, resources and opportunities for Alzheimer's families to share emotions and insights. The site – unlike any other existing Web site – will help the public understand Alzheimer's by weaving together personal stories, science and history. Through interactive features, the site will give visitors insight into such topics as: What is it like to have Alzheimer's? What's normal and what's not? Who's at risk? How do we live well with Alzheimer's?

In addition, the Alzheimer's Association is looking for volunteers to host House Parties to watch ***The Forgetting***, discuss and take action. For those interested in more information on hosting a house party contact your local Alzheimer's Association Chapter or use the following Internet link:

<http://www.alz.org/Advocates/forgetting.html>

### *Talking With Your Doctor* By Carlos Escobar, M.D.

Do not hesitate or fear asking your doctors as many questions as needed regarding your medical conditions. It's important to understand your doctor's answers. Ask for written instructions if necessary. Communication should help you and your doctor build a partnership.

The following is a list of tips that can make your appointment more productive:

- Be prepared: make a list of your concerns.
- Bring the bottles of ALL medications prescribed by ALL of your physicians.
- Bring the bottles of ALL the over-the-counter medications and herbal products you use.
- Mention the amount of caffeine and caffeinated products you consume (coffee, tea and cola).
- Report your habits: alcohol and smoking.
- Cognitive skills such as the ability to hear, read and understand instructions may also decrease with age; therefore, consider bringing a family member or friend.

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- Confidently report any changes you have noticed in your emotions or personality such as sadness, crying spells, isolation, sleep disturbance, unusual behavior or paranoia. Paranoia can be manifested as suspiciousness, extreme jealousy, feeling somebody is spying on your house, mistaking a relative or friend, or refusal of medication or meals.
- Ask your doctor to depict in a simple drawing as he explains your illness or the effects of medications.
- Ask your doctor to speak in layman's terms
- Learn to build your own medical file. Put copies of lab results, X-ray reports and other studies in a folder and carry it with you to your appointments.

## Hints for Daily Living

Laura L. Matos

Coping on a daily basis with an AD patient is a highly consuming, task—especially during the first stage where the patient and caregiver recognize something is wrong, but have difficulty accepting change.

Accomplishing daily living activities can become an overwhelming stressor. Very often the caregiver is drained of all energy, enthusiasm and empathy long before the day finishes.

In support groups for those in the first stages of the disease, patients exhibit a strong desire to maintain control of their lives, even though they realize they are starting to forget things or experience lapses in judgment. This desire to remain in control regardless of diminished abilities can present difficult situations for the caregiver in several key areas of daily life, including: control of food consumption, opposition to personal hygiene routines and the re-education of bladder and bowel control.



The majority of caregivers find that structuring the day with schedules and patterns results in a less stressful day. They are allowed to accomplish more care-oriented tasks throughout the day, as well as enjoy free time for themselves and with their patients.

The next page offers some ways to address common every-day situations involving personal control issues.

### **Texas Alzheimer's News**

is published by:

Texas Department of Health  
Adult Health Program  
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Austin, Texas 78756-3199  
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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](http://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.

Publication  
#42-10500

*When your patient DOES NOT WANT TO . . .*

**Brush his/her teeth**

*You might WANT TO . . .*  
After meals: Wearing a disposable glove, wrap soft gauze wet in any over the counter mouth solution around your index finger. Clean the cavity. Use dental floss as often as once a day, especially at night. The threaded “Gentle Gum Care” is a favorite.

**Use disposable diapers**

Wait until the night medications have been given and, when your patient is falling asleep, gently put on the diapers. The following morning, praise the convenience of using diapers.

**Sleep in his/her own bed**

Explore, modify and reassure the patient that it’s a safe place. Go to sleep in the same room for several nights. After a while, they will usually “re-recognize” their own territories.

**Eat a meal**

Especially during the agitation states: Use plain tablecloths, dishes and cups. Neutral colors without prints are recommended. Use cups with handles and wide rims. Place no decorations or other distracting pieces on the table. Do not “overcrowd” the food. Serve a single item at a time in small portions. Fractioned meals are recommended. Check texture and temperature before serving.

**Relinquish control of money**

Have the patient with you while writing checks. Have him/her pile some coins or sort bills if possible. Let them carry a small wallet or purse with their ID’s and a few coins and single bills.

**Change soiled clothes**

Patients exhibit a tendency to stick with some clothes even though they are filthy. Have several sets of the same garment, changing as often as necessary.

Never forget that you, as a caregiver, are your patient’s only source of security, pleasure and hope. You are extremely important to them! Avoid conduct that might cause anxiety or fear. Take a little time out for yourself if you lose control. Voluntarily add to each of your actions a little compassion, tenderness and love. Soon you will find these little touches are just another part of your routine.

***Smile! Your patient will imitate your actions!***



*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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