TEXAS DEPARTMENT OF HEALTH

Alzheimer's Disease Newsletter

SPRING SUMMER 1994

Driving and Alzheimer's Disease

Kevin F. Gray, M.D.

Here in the United States, the right to drive has become almost an inalienable right, and there is perhaps no single greater symbol of individual freedom than the automobile. For seniors, driving can be tangible proof of "aging gracefully," but the loss of driving privileges often represents the end of independence. By the year 2000, one in three drivers will be older than 55, and increasingly at risk for developing Alzheimer's disease or some other dementing illness. As America ages, physicians, caregivers and family members will be drawn more and more into complicated legal, moral, and ethical dilemmas involving older drivers.

Older, "more careful" drivers have a low rate of accidents per year, although they have a high rate of accidents per mile since they drive less. A recent study of demented persons who continue to drive found that one out of every 10 demented drivers will crash annually. This rate is 1.4 times worse than all drivers and 2.5 times worse than drivers over age 65. Nevertheless, the accident rate for demented drivers is 1.5 times better than the rate for 16-24 year old males, a group that our society does not prohibit from driving. The study concluded that in the first three years following the onset of dementia symptoms, Alzheimer's victims drive at a level of accident risk that our society deems acceptable. Fortunately, perhaps half of all drivers with dementia voluntarily stop driving within three years of the onset of their illness. Driving skills deteriorate to clearly unacceptable levels as dementia progresses. By the fourth year after symptom onset, one out of every six demented drivers is involved in a traffic accident. When drivers with mild Alzheimer's disease were road-tested, approximately 40% failed. Of the 60% who passed, one-fourth confessed some concerns about their ability to continue to drive, but all who failed their driving test felt that they were perfectly capable of driving properly! This reflects the dramatic lack of judgement and insight so often seen in Alzheimer's disease.

Across the country, various laws are under consideration to help remove impaired drivers from the road. Currently, the State of Texas does not require special driving tests for the elderly, nor require the elderly to renew their licenses more frequently. Some vision testing is required, but Texas physicians legally are not required to report Alzheimer's disease, and mail-in license renewal is allowed at any age. Tragically, many demented people continue to drive long past the time when they can do so with reasonable safety. Often families look to their physician to compel an impaired loved one to stop driving, even though many physicians do not routinely ask their older patients about driving. For a variety of reasons, families do not always bring up

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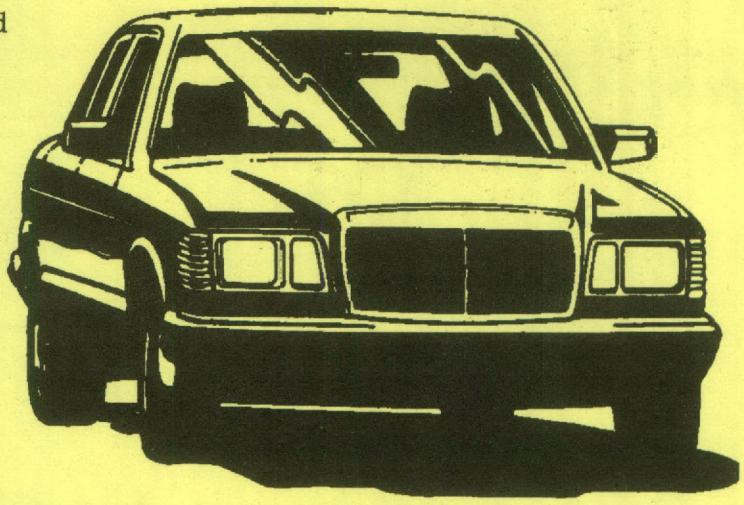
ALSO IN THIS ISSUE:

their concerns, perhaps feeling that "it would kill them to give up their driver's license," or "it would break their heart to stop driving." Remember, based on the studies mentioned above, there is little justification to revoke someone's driver's license at the earliest hint of cognitive decline. Instead, the judgement of physicians and families can be thoughtfully exercised over approximately a three-year symptomatic period. Concerned physicians and families both can report demented drivers to the Texas Department of Health Medical Advisory Board for Driver's Licensing (512-834-6740). Reporting impaired older drivers not only avoids potential liability, but does not automatically "take away" anyone's license.



Understandably, families have mixed feelings about stopping their loved ones from driving. For some older couples, the wife may never have learned to drive, and the Alzheimer's victim may be the only driver. This is especially a problem in isolated rural areas. Families who believe that their demented elder is probably "OK" driving on short trips should consider their own driving experience. When learning to drive, most of us had to think carefully about every step involved in driving the car. These days, after years of practice, actually driving the car is one thing we do not think much about, since our "habit-memory" does the job for us. Thus, the demented driver can give the impression of competence on familiar, nearby routes, but may not be able to react in a timely or appropriate fashion when confronted with the unexpected (e.g., road construction, wrecks, bad-weather, ambulances, etc.). Spouses who drive should offer to do so at every opportunity, since the common practice of directing the demented driver from the passenger's seat is unsafe. Tests show that verbal cues do not reliably improve performance in Alzheimer's disease due to impairment of language and executive abilities.

When a demented person refuses to voluntarily refrain from driving, concerned family members should get together and discuss creative options. It is important for everyone not to argue with the demented driver, as this tactic often results in unnecessary anger and friction. Although honesty may be the best policy, in real life, duplicity usually works better! The simple notion of "out of sight, out of mind" can be an important strategy. The demented driver's car can be taken to a cooperative relative's house (or even just parked around the block) until it is forgotten. Families can tell prearranged stories of the car being "wrecked," or taken in for much-needed "repairs" that are found to "cost too much," requiring the car to be "sold." Perhaps a "letter" can arrive, announcing expensive car insurance premiums, or even a "factory recall." Remember that it is easier to disable the car than to disable the patient. Disconnecting the battery or having "duplicate" car keys made that will not actually start the car can provide families with an excuse to have the car "taken in for repairs." With cooperation from a garage, a silent alarm or security system can be installed to prevent unauthorized operation of the car. Families should keep in mind that these suggestions are not shameful recipes for disloyalty and deceit, but rather are practical, face-saving, safety techniques for all concerned. By being "slick," families can accomplish the important goal of stopping their impaired loved one from continuing to drive, and avoid unnecessary confrontation and conflict. In time, the demented person's memories and habits for driving the car on a day-to-day basis will fade away....

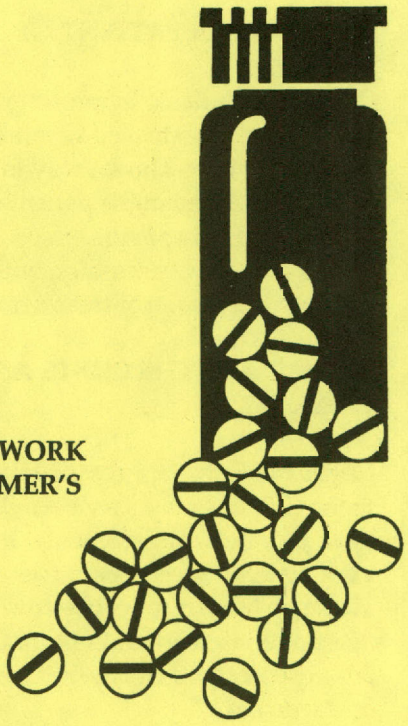
Dr. Gray is the Director of Alzheimer's Research at the Dallas Veterans Administration.

The Alzheimer's Disease newsletter is prepared by the staff of the Texas Department of Health Alzheimer's Program. For more information about Alzheimer's Disease contact:

Veronda L. Durden, Program Director
1-800-242-3399

COGNEX—

WHAT'S IT ALL ABOUT?



Alzheimer's Disease touches the lives of more than four million Americans and their families. Each year over a 100,000 people die as a result of Alzheimer's disease. Until recently, medical professionals could not provide any medication to battle Alzheimer's. The release of Cognex in September offers hope to victims, their families and physicians in the battle against this progressive, degenerative disease. It is important to note that Cognex is not a cure, and there is no evidence that it affects the progression of the disease. However, studies have demonstrated that some patients may experience a small temporary improvement in symptoms such as memory loss.

As with any new medication there are often many questions and concerns about the medication. The following are answers to frequently asked questions about Cognex.

WHAT IS COGNEX?

Cognex (also called tetrahydroaminoacridine, tacrine or THA) is the first drug approved by the U.S. Food and Drug Administration specifically to treat Alzheimer's disease. It is not a cure for Alzheimer's disease, nor does it appear to stop the progression of the disease. Cognex is made by Parke-Davis, a division of the Warner-Lambert Company.

HOW DOES COGNEX WORK?

The billions of nerve cells in the brain communicate using chemicals one of which is called acetylcholine. Normally, acetylcholine is produced by nerve cells, released and then broken down. Cognex slows the breakdown of acetylcholine present in the brain. Since the amount of acetylcholine is decreased in the brains of patients with Alzheimer's disease, increasing the amount of this chemical may enable nerve cells to communicate better. This, in turn, may relieve some of the memory impairment and other symptoms associated with Alzheimer's disease.

DOES COGNEX WORK FOR ALL ALZHEIMER'S PATIENTS?

From the information presently available, Cognex will not improve the condition of the majority of Alzheimer's patients. To date, Cognex has only been studied in patients who had Alzheimer's disease of mild to moderate severity and otherwise were in generally good health. There is no way to predict whether or not Cognex will help an Alzheimer patient. The only way to determine what effects Cognex will have on an individual patient is for the patient to try the drug.

ARE THERE ANY SIDE EFFECTS OF COGNEX?

The most common side effect of Cognex is an increase in a particular liver enzyme (alanine aminotransferase, or ALT). However, there is no way to predetermine before trying the drug whether any individual patient will experience this side effect. When a patient starts taking Cognex, blood will be drawn on a regular basis to measure this liver enzyme. Through regular monitoring, the doctor will learn whether the patient shows this sensitivity, and will be able to make treatment decisions accordingly.

Other side effects of Cognex may include nausea, vomiting, diarrhea, abdominal pain, indigestion and skin rash.

Any time a person begins taking a new drug, the doctor, patient and family should discuss what potential side effects the drug may have, and how the drug may interact with other drugs being taken (prescription or over-the-counter).

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How can a patient get Cognex?

Cognex is available by prescription from your doctor and is currently stocked in most pharmacies. Because there is no known way to predict whether an individual Alzheimer's patient will experience beneficial effects or side effects, it is important to have a thorough discussion with your doctor about the possible results of treatment with Cognex.

What are the costs associated with Cognex?

Cognex will cost approximately $120-$140 per month. Prices may vary between pharmacies. If you have private or supplemental insurance, contact your company representative to discuss coverage. Those on Medicare will be covered for doctor visits and lab work but not for the prescription. All expenses will be covered for those patients on Medicaid.

What kinds of questions should you ask your doctor?

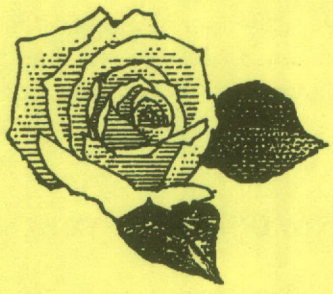
- What are the potential benefits of taking Cognex?
- What drugs (prescription and nonprescription) might interact with Cognex?
- How might Cognex affect other medical conditions?
- How will we know Cognex is working?

Are there other drugs available to treat symptoms of Alzheimer's disease?

Several types of drugs may be useful in treating the behavioral symptoms of Alzheimer's disease. Behavioral symptoms may include depression, agitation, anxiety, sleep disturbances, hallucinations, delusions and others. In an Alzheimer patient experiencing such symptoms, treatment options should be discussed with the patient's doctor.

Prepared by Veronda L. Durden, Director of the Alzheimer's Program.

WHAT ALZHEIMER'S IS NOT



- Alzheimer's is **not** a normal part of aging. It is a disease that is fatal and, so far, incurable.
- It is **not** "hardening of the arteries," the once-classic explanation for the symptoms of senile dementia. ("Senile" means old, "dementia" means deprived of mind.)
- It is **not** depression, although Alzheimer's sufferers may become depressed about their declining mental powers.
- It is **not** something you can catch from someone else.

DIAGNOSING ALZHEIMER'S DISEASE

Many conditions that produce "Alzheimer-like" symptoms can be treated. That is why it is crucial that a person with suspected AD have a complete medical and neurological workup. Other possible causes of dementia like depression, drug overdose, thyroid disease, poor nutrition, brain tumor, and head injuries are often misdiagnosed as Alzheimer's. In addition, there are "related disorders" that can cause dementia: Huntington's disease, Parkinson's disease, Creutzfeldt's-Jakob disease, and Pick's disease.

There is no single diagnostic test for Alzheimer's disease. Therefore, a complete medical and neurologic evaluation is strongly recommended when a person experiences symptoms of dementia.

A complete evaluation should include:

- A detailed medical history
- A thorough physical and neurologic examination
- A mental test that evaluates orientation, attention, memory and the ability to calculate, read, write, copy drawings, repeat ideas, understand, and make judgements
- A psychiatric test to rule out psychiatric disorders
- Neuropsychological testing
- Routine laboratory tests to exclude treatable causes of dementia

This diagnostic process tries to rule out other causes and is about 90 percent accurate when performed by doctors and specialists experienced in the diagnosis of Alzheimer's disease - usually a neurologist or geriatrician. The only way to really diagnose Alzheimer's is by examining brain tissue for characteristic abnormalities under a microscope, usually at autopsy.

Source: Coping & Sharing: Living With Alzheimer's. AARP 1993

If someone you know has Alzheimer's Disease, he or she may be able to participate in medication studies.

For More information, please call the University of Texas Southwestern Medical Center Alzheimer's Disease Research Center at:

214/688-8696.

REMEMBER ME

Please remember me when the morning light breaks fair,
I long to know you still care.
Please remember me when the sun shines high in the sky.
Can't you feel my presence nearby?

Please remember me when evening shadows are lengthening.
I need to know your love to me you are sending.
Please remember me in the still cold dark of night.
I know your love will bring a new light.

Still one glorious day, God's love will bring a new light.
A light that will flood our lives and shine ever so bright.
So, please remember me, for you see I don't remember you.
And remembering me, will carry us all the way through,
and yes, your remembrance will have to do.

Audrey Ball

CAREGIVER CORNER

Hello Veronda,

Here are the photos I promised. Mr. Morgan's puppy is named Shady. As you can see Mr. Morgan has a big smile on his face.

As I told you, since Shady arrived there has been a significant change in Mr. Morgan's behavior. He will sit for hours holding the puppy while she sleeps. He talks to her all the time. Although he can't tell you her name, he understands when you ask him about his puppy.

He now has something to care for and love. Before Shady arrived he walked all the time and would not sit for any amount of time. That has all changed. I truly see the change and at this time it is for the better. Shady has given him a purpose. Hope you enjoy the photos.

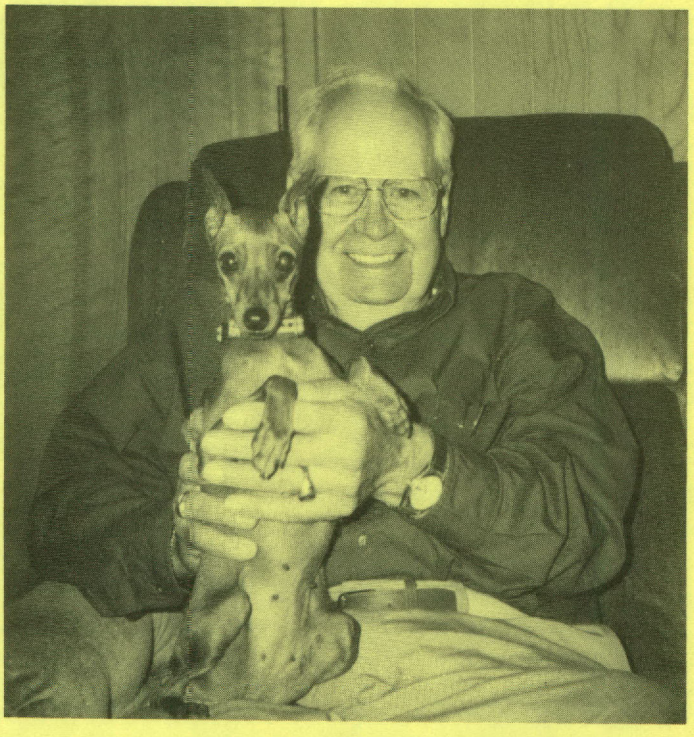
God Bless,

Ina Ellis

P.S.Thanks for letting me talk and most of all thanks for caring and giving me support.

Editor's Note

Ms. Ellis began taking care of Mr. Morgan after his wife died of cancer in 1992. Mr. Morgan lives in Temple and is a retired railroader. Ina and Mr. Morgan's days are full of activities. Mr. Ellis enjoys visiting with friends at the Masonic Temple, he likes to listen to country western music, work in the garden, go to the movies, and attend church. Mr. Morgan's biggest source of enjoyment these days is his puppy Shady. Ms. Ellis reports that Mr. Morgan will sit for hours and hold Shady as she sleeps.



Mr. Morgan enjoys Shady, (left), and the Riverwalk in San Antonio with Ms. Ellis, (above).

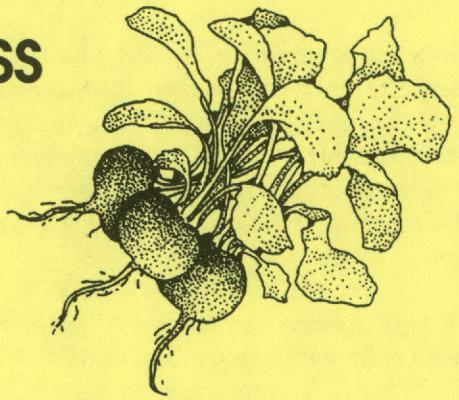
Hints for Family Caregivers

Learning how to cope with the effects of Alzheimer's disease and the increasing needs of your loved one will help you deal with your own stress and anxiety. The following suggestions are offered for family caregivers:

- ❤ Take one day at a time, but prepare for the future.
- ❤ Recognize which problems you can do something about and which are beyond your or anyone else's control.
- ❤ Be realistic about your abilities and how much you can do. Don't try to do it all yourself. Don't expect to accomplish all the things you were able to do before you became a caregiver.
- ❤ Be realistic about your loved one's changing abilities. Enjoy the memories of what you did in the past, but accept that the person has different needs, abilities, and interests now. Your relationship will be different than it was before, but it still can be meaningful and rewarding for both of you.
- ❤ Be forgiving of yourself if things don't go just right - your loved one may quickly forget an oversight or mishap.
- ❤ Find out what resources are available and use them. Ask family and friends to help and accept their help when offered. If you think other family members aren't helping as much as they could, talk to them honestly.
- ❤ Be good to yourself. Remember that you deserve some pleasure; take time to see a movie or visit with friends.
- ❤ Keep your sense of humor.
- ❤ Find ways to express your feelings. Find a friend you can talk to or attend a support group meeting.

Adapted from "Especially for the Alzheimer Caregiver" from the Alzheimer's Association.

INSTANT GARDEN OF SUCCESS



Plant 5 Rows of Peas
Preparedness, Promptness, Perseverance, Politeness, Prayer.

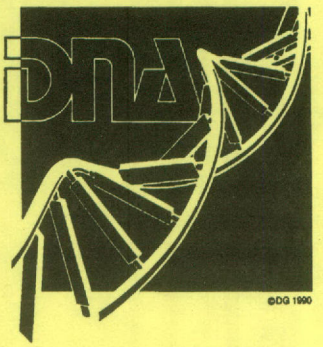
Include 3 Rows of Squash
Squash gossip, Squash criticism, Squash indifference.

Add 5 Rows of Lettuce
Let us be faithful, Let us be loyal, Let us be truthful, Let us be unselfish, Let us love one another.

No Garden is really complete without Turnips
Turn up happy, Turn up with a smile, Turn up with a new idea, Turn up with a real determination.

From the Albuquerque NM Alzheimer's Association Chapter

Update on DNA Research Bank



Dr. Shirley Poduslo, professor of neurology at Texas Tech School of Medicine, directs the DNA research project which is funded by a grant from the Texas Department of Health. DNA, or deoxyribonucleic acid, is the principal carrier of genetic information in humans. Found in the chromosomes of cells, DNA replicates during cell division. Several diseases can occur if genes are abnormal, possibly including Alzheimer's.

Dr. Poduslo and her staff collect two vials of blood from each participant, answer questions about genetic research, and arrange for shipping blood samples from family unit members living in other areas. For each patient involved, it is important to obtain blood samples from as many of their family members as possible and gather complete family history information. Families with a history of Alzheimer's disease are urged to participate. Data derived from the study of several hundred blood samples could reveal new information concerning these disorders. Slides prepared can be used for continuing research decades in the future.

Sampling events for the DNA Bank of Texas Tech University Health Sciences Center held during the past year have been characterized by an atmosphere of cooperation and enthusiasm. Brownfield, Lamesa, Big Spring, Odessa, Abilene, Tulia, Amarillo, and Plainview here been testing sites.

Since the beginning of the DNA Bank approximately 600 blood donors have contributed blood for the genetic study with nearly 250 different family units represented. Some 33 early onset cases have been identified thus far. Early onset patients manifest symptoms of the disease before the age of 65 years.

"If we can learn what causes Alzheimer's then we can move on with two goals in mind," Dr. Poduslo said. "We can attempt to prevent it from happening and/or find ways to treat it in early stages before a lot of brain cells die."

In the organizational phase of setting up the DNA Bank, 20 blood samples have been assigned to each technician as her/his particular responsibility. Drawing and processing blood samples from patients and family members, transforming and feeding lymphocytes to grow permanent cell lines, and completing family histories are joint activities of the staff.

Representatives of Alzheimer's Support Groups, churches, or other community organizations interested in sponsoring a DNA collection event should contact Mrs. Coke Toliver, Volunteer Coordinator for the DNA project, by calling (806) 637-3251. For more information on DNA research Dr. Poduslo may be contacted at (806) 743-2789.

Submitted by Oleta Toliver, Volunteer Coordinator for the DNA Bank

News You Can Use. . .
APOE Blood Test Alert

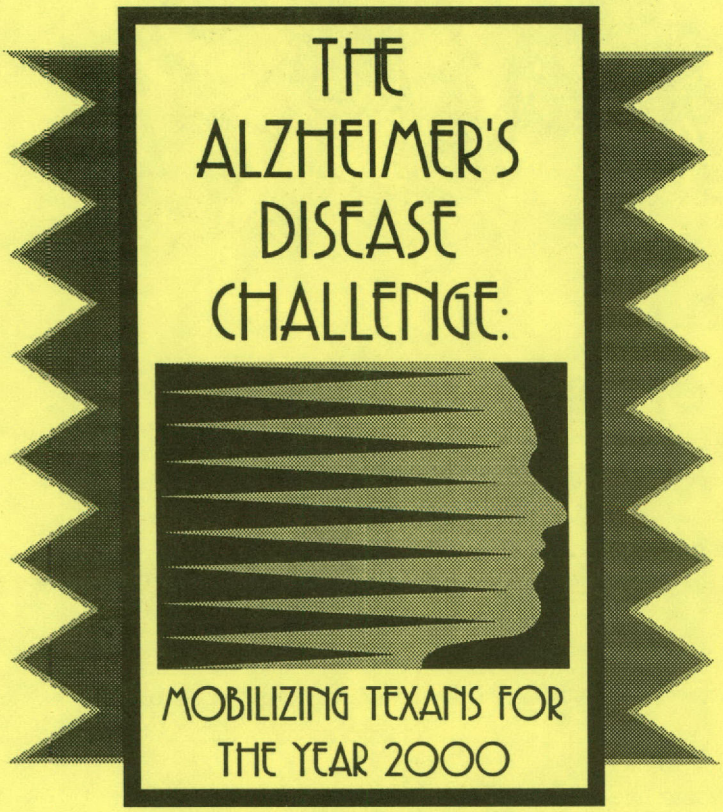
The following information was forwarded from the National Alzheimer's Association. Several companies are now actively marketing their blood tests for ApoE, and encouraging people to take the test to predict whether they will develop Alzheimer's disease. This is the Alzheimer's Association's position on this blood test:

- There is no clinical proof that this blood test can truly predict one's risk for Alzheimer's disease. That is, the value of the blood test is theoretical, and has not been tested sufficiently on people to determine whether it is, in fact, a useful predictor.
- There is no way to use the test results to determine a person's degree of risk (i.e., the odds of contracting the disease) even if the ApoE gene variant were found.
- There is no treatment available for the ApoE gene variant.

Therefore, the value of the blood test for Alzheimer's is questionable, and physicians may see no purpose in ordering the test. Rather than focus on "what if" scenarios, it would be far more productive to continue to encourage people to see their physicians for a thorough examination and diagnosis of questionable symptoms. That way they are more able to get the kind of evaluation and, possibly, treatment that will help them.

UPCOMING EVENT..

The Alzheimer's Disease Challenge: Mobilizing Texans For The Year 2000



WHEN: November 4-5, 1994

WHERE: Wyndham Hotel, Austin, Texas

WHO SHOULD ATTEND: Individuals who provide care at all levels to persons with Alzheimer's Disease including: family and professional caregivers, health care professionals, medical professionals, mental health professionals, and others desiring information about Alzheimer's Disease.

For registration information contact: Veronda L. Durden, Alzheimer's Program at 1-800-242-3399

In recognition of the diverse needs of Alzheimer's caregivers and families throughout Texas, the Texas Department of Health's Alzheimer's Program and the Texas Council on Alzheimer's Disease and Related Disorders are planning the first statewide conference on Alzheimer's Disease in Texas. Information will be presented on Alzheimer's disease research, new medical treatments for Alzheimer's patients, caregiving strategies for coping with the symptoms and behaviors associated with dementia, legal and financial needs of the patient and family, supportive resources in Texas, and many other relevant and current topics.

TODAY

When time is worsening daily
With a loved one, man or wife,
Today, of all the rest, becomes
The best day of your life.

Time is a gift, your heartbeats fuel,
A privilege without price,
So seize each moment like a jewel,
It will not pass by twice!

Jean Wood

Communicating with a Memory-Impaired Person

Communication is not just a two-way street. It occurs on two levels—verbal and non-verbal. The tone of your voice and facial expressions are just as important as the actual words, especially when dealing with someone who has Alzheimer's disease. Here are some general guidelines to remember:

VERBAL

- Speak slowly and simply. Use short sentences and words. Avoid complex conversations or instructions.
- Use nouns and proper names frequently. Avoid using "he," "she," "it", "those," etc. Cue the person with necessary information.
- Begin conversations, especially at night, by calling the person by name, touching them gently, and identifying yourself if needed.
- Discuss only concrete actions and objects. The person cannot relate to concepts.
- Don't ask multiple-choice questions; this adds to confusion and stress. Try to ask questions that can be answered with a "yes" or "no", or with a gesture.
- Use simple directions for tasks that you are assigning. Go one step at a time.

NONVERBAL

- Stand in front of the person, at eye level; do not startle them by approaching them from behind.
- Walk with the person if he or she starts to walk away. Do not restrain them.
- In general, remember: the person has an increased awareness of non-verbal cues as the disease progresses and that the Alzheimer's patient is extremely sensitive to the emotional climate of the environment.

AUDIOVISUALS AVAILABLE

FROM THE TEXAS DEPARTMENT OF HEALTH AUDIOVISUAL LIBRARY

(512) 458-7260

The following are some of the audiovisuals on Aging, Alzheimer's disease and Long Term Care Facilities available for free short-term loan:

Aging - 722. The many patterns of aging and the common stereotypes about the old are explored.

Alzheimer's Disease: Stolen Tomorrows - 4307. Describes the various stages of Alzheimer's disease and provides coping strategies for people whose lives are touched by the disease.

Another Home for Mom - 5408. Gives viewers an understanding of the dilemmas faced by many caregiving families, and helps families to articulate their feelings about choosing institutional care for their relative.

Blackberries in the Dark - 5125. Based on the children's book by the same title. Tells of nine year old Austin and his grandmother and their personal struggle to come to terms with the recent death of Austin's grandfather.

Can't Afford to Grow Old - 4886. Analyzes the impact of the aging of America on our strained health care system.

Creative Interventions With The Alzheimer's Patient: Understanding Behaviors - 5397. A lecture by Mary Lucero concerning creative ways to meet the needs of dementia patients, particularly those with Alzheimer's Disease.

Crosscurrents: A Look at Ageism - 521. Peg, 15, and her grandfather spend a day together fishing. They discuss, from opposite perspectives, their views on aging and the elderly.

A Day In the Life of Nancy Moore - 5368. Developed specifically for nurses' aides who care for patients with Alzheimer's Disease.

Eating For Your Health - 4700. Teaches how diet affects health, and how dietary needs change with age.

Facing Alzheimer's: Legal and Financial Considerations - 5314. Provides information on where and how to find professional help such as attorneys or financial advisors.

Gerontology: Learning About Aging - 522. Provides an overview of gerontology - the study of aging and the elderly.

The Heart Has No Wrinkles - 5313. Combines interviews and a realistic dramatic situation to explore the issue of sexuality and older people.

Helping Hands: The Right Way to Choose a Nursing Home - 5121. Provides basic information on selecting a proper nursing home.

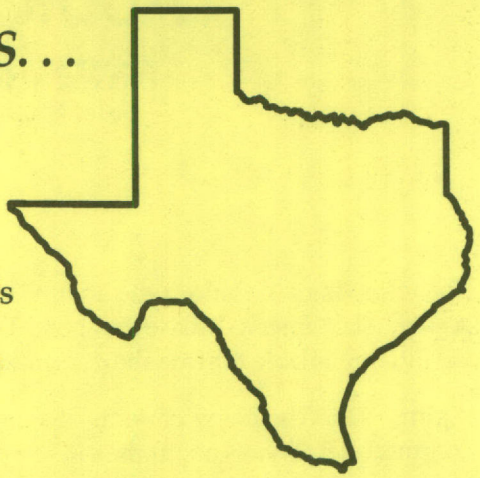
Managing With Alzheimer's Disease - 4404. Teaches specific skills for caregivers within the home of the Alzheimer's patient.

Sexuality and Aging - 4471. This factual and personalized account of sexuality and older Americans is presented through interviews with psychologists, sexologists, older adults and physicians.

Stress in the Later Years - 4232. Describes how the special stresses of older people (loss, loneliness, retirement, etc.) can cause physical disorders.

Universal Precautions: Guidelines for Long Tern Care Facilities - 4997. Explains how health care workers exposed to blood and body fluids are at risk for contracting Hepatitis B and HIV unless universal precautions are taken to protect them.

ALZHEIMER'S DISEASE IN TEXAS. . .



BY THE YEAR 2000 THERE WILL BE:

* 1.9 million Texans age 65 and older
* Over 300,000 Texans age 65 and over with Alzheimer's
* Over 59,000 Texans age 65 and over in nursing homes

DID YOU KNOW:

* Alzheimer's disease is estimated to be the fourth or fifth leading cause of death in the United States, killing more than 100,000 persons annually
* The average duration of Alzheimer's is 8 years
* Alzheimer's disease costs Texans over 2 billion dollars a year
* Home care for an Alzheimer's patient averages $18,000 per year
* Institutional care for an Alzheimer's patient averages between $24,000 to $36,000 per year
* The incidence of the disease in women is higher than in men

Alzheimer's Disease Newsletter
Texas Department of Health
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Austin, Texas 78756

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