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Updates in the Treatment of Alzheimer's (Part 2)

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Alzheimer's disease is a progressive degenerative disorder affecting chemical systems located in various regions of the brain. In the last issue of this Newsletter we discussed management of the behavioral changes which sometimes occur in Alzheimer's patients. We also reviewed experimental drug treatments designed to improve the cholinergic chemical system. It is important to realize that cholinergic drugs affect only one of the several disturbed chemical systems involved in Alzheimer's disease. These drugs cannot reverse or stop the brain cell changes that occur in the disease. So although they may improve symptoms in some patients, cholinergic enhancing drugs are not a cure. We are not likely to develop a cure for Alzheimer's until the cause or causes are clearly established.

A wide range of Alzheimer's drugs are currently being developed to provide symptomatic relief or slow the progression of the disease. Experimental trials are underway to look for more powerful cholinergic drugs and to look for drugs that affect other brain chemical systems, like serotonin and norepinephrine. A strategy for future symptomatic treatment may involve prescribing multiple drugs to affect multiple chemical systems. Another strategy is based upon the fact that brain cells of Alzheimer's patients undergo a process called oxidation. One study showed that an antioxidant medication called deprenyl seemed to slow the progression of Parkinson's disease, a degenerative brain condition related to Alzheimer's disease. Deprenyl's effects on the dopamine chemical system may have contributed to the drug's benefits. An experimental trial sponsored by the National Institute of Aging is examining use of the antioxidants tocopherol and selegiline (Deprenyl) for slowing the progression of

Alzheimer's disease. Other research studies have shown that the brain produces growth factors which normally help to maintain brain cells. These growth factors are effective only if they exist in high concentration close to the cells they maintain, so they cannot be given. Since brain cells seem to mysteriously die off in Alzheimer's disease future trials may attempt to deliver growth factors to the brains of Alzheimer's patients, either by implanting tissues which produce these factors or by infusing growth factors directly into the brain.

Two major microscopic changes occur in the tissues of Alzheimer's disease patients. The cellular skeleton of neurons or nerve cells breaks down. We do not know what initiates this breakdown, but have identified markers on cells destined to succumb to these changes. By understanding what produces these markers, we may learn what kinds of drugs

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could prevent these neuronal changes in Alzheimer's disease. Changes also occur in the spaces between cells, and the predominant change is the accumulation of a fragment of amyloid protein. Everyone's brain produces amyloid, even the fragment (known as beta-amyloid) that accumulates abnormally in Alzheimer's disease. The beta-amyloid fragment can be found in cerebrospinal fluid (fluid that bathes the brain, obtainable by a spinal tap), although we do not yet know if cerebrospinal fluid levels are consistently higher in Alzheimer's patients than in normal individuals. Current lines of research include ways to modify the normal biochemical process that produces this amyloid fragment and possibly shut down its production.

In summary, we have discussed in this and the previous issue of the Newsletter that treatment of Alzheimer's disease involves taking care of the patient and his or her family as well. Education, counseling, and respite care are all important aspects of treatment which should be addressed in every case. Secondary effects of Alzheimer's disease such

as sleep disturbances, depression, agitation or psychotic features (hallucinations, paranoia) should be treated.

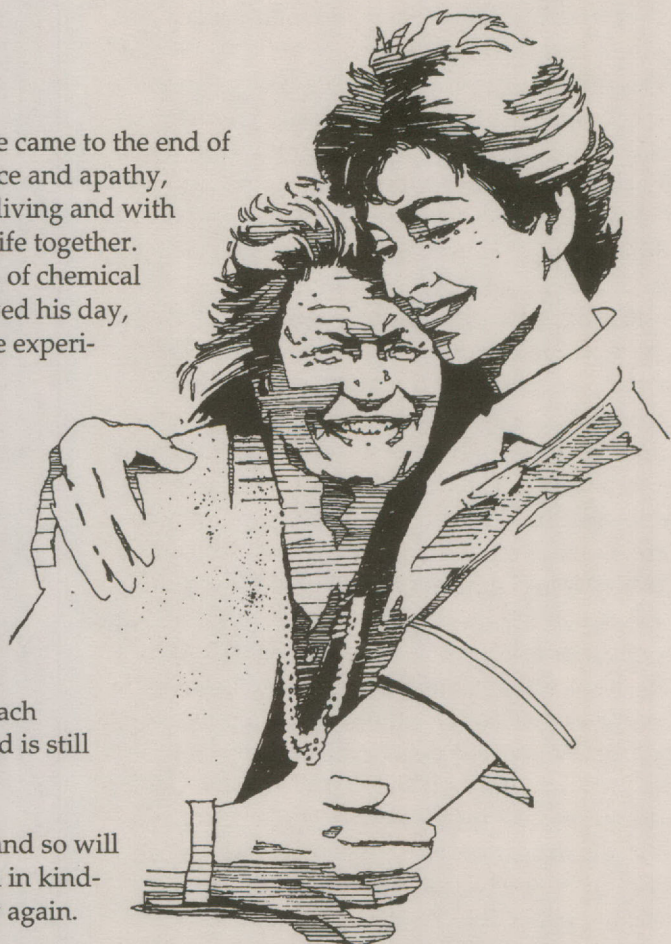
Treatments for the primary process of Alzheimer's disease remain experimental, but have been informed by recent advances in understanding the chemical and tissue changes seen in this disease. The National Institutes of Health (NIH) have contributed to research and treatment of Alzheimer's disease by establishing Alzheimer's Disease Research Centers for clinical care and basic science research. Baylor College of Medicine is one of these centers. The NIH has also established a national consortium of centers for rapidly testing potential new therapies, known as the Alzheimer's Disease Co-operative Study Unit. This consortium includes all of the federally funded Alzheimer's Research Centers. Individuals can learn more about Alzheimer's disease and experimental therapies by calling the Texas Department of Health's 800 number, the Alzheimer's Disease Association (national or local chapters) or an Alzheimer's Research Center.

Kindness. . .

A psychiatrist pondered the state of the world as he came to the end of a long, difficult day. He had dealt with both violence and apathy, with a young woman who saw no reason to go on living and with a man who was sure he could never again put his life together. Some of the problems were the result, he reasoned, of chemical imbalance or of physical ailments; but as he reviewed his day, and compared it with most other days and with the experience of his colleagues in psychiatry, he offered an estimate: At least half of those who are mentally ill could have been spared their illness by "simple human kindness."

The time to do kindness, to think it, to speak it, is now. If it be true, that more than half of those mentally ill could have been spared their illness by "simple human kindness," then how many other lesser pains could be avoided - and how much more happiness could be wrought - if only each of us could share a bit more kindness? The demand is still far greater than the supply.

This is the day to be kind. Tomorrow will be too, and so will the next day. But today is the day to be born again in kindness, for you and I won't pass this day, or this way again.



Alzheimer's Disease: What Can Families Expect?



Alzheimer's Disease (AD) is the fourth leading cause of death among Americans over the age of sixty-five. AD is a degenerative brain disease that causes progressive loss of memory and mental abilities. At present there is no cause, cure or treatment.

The victims of AD include the individual and their family. Once an individual is diagnosed as having Alzheimer's, families have many questions and concerns. Most families do not know what to expect and are not prepared for the devastating impact the disease will have on the individual and the family.

The course of Alzheimer's differs with each patient. For most patients, the disease progresses slowly over a period of five to ten years, or longer. Deterioration generally occurs in one or more of the following:

- Memory, concentration and orientation
- Mood and behavior
- Language and speech
- Movement and orientation

The changing symptoms accompanying the progression of Alzheimer's disease fall into two categories: cognitive and behavioral. The cognitive changes are related to declining intellectual abilities and cortical functioning. They include deterioration in concentration, calculation, memory, judgement, orientation, language, self-care, and gait, with the eventual loss of ambulatory ability. To date there is no treatment available to alleviate the primary cognitive symptoms of AD.

The second area of change accompanying AD, behavioral changes, are amenable to pharmacological (medication) and, to some extent, psychotherapeutic intervention. Behavioral symptoms occur in about 50% of Alzheimer's patients and such interventions can make a significant difference in the quality of life of both the Alzheimer's patient and the caregiver.

HOW DOES ALZHEIMER'S PROGRESS?

Alzheimer's is usually described in terms of early, middle and late stages. These stages are general, rather than specific. Each individual is unique. The

symptoms that occur, when they occur and how long they last will vary with each patient.

EARLY STAGE - Cognitive Changes

Early in the disease, short-term memory loss occurs. Other problems accompany this:

- Unusual forgetfulness
- Difficulty in concentrating
- Difficulty in finding the right word
- Making poor choices or showing bad judgement

It is important to note that memory loss in itself is not a sign of AD. Many people normally have some memory loss as they age. In Alzheimer's disease, the problem will worsen steadily.

EARLY STAGE - Behavioral Changes

During this stage, the subtle changes in personality may occur. Depression is one of the more common symptoms in the early stage of the disease. There are signs of depression. The person may:

- Seem sadder
- Be more quiet or negative than usual
- Sleep too much or too little
- Lose an unusual amount of weight
- Not seem aware of or interested in things or events

People living alone are particularly vulnerable at this stage. At times, they cannot recall their address, telephone number, or other significant information about their lives. The area of memory lapse varies from moment to moment.

MIDDLE STAGE - Cognitive Changes

The middle stages of AD is characterized by more and more severe memory loss. For example, the patient:

- Is often not able to recognize family and friends
- Loses language ability and cannot articulate needs
- Begins to require assistance with basic activities of daily life such as bathing and toileting

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- Suffers memory deterioration to a fragmentary knowledge of address and whereabouts
- Frequently cannot identify the spouse upon whom survival depends

Alzheimer's patients in these stages cannot survive alone in the community. The person may be unable to remember even basic safety rules. The person requires close supervision. This part of caregiving can be difficult.

MIDDLE STAGE - Behavior Changes

The individual may exhibit striking personality changes. Alzheimer's reduces the patient's ability to perform all adult activities so that the person, increasingly, can neither understand nor make one's self understood. Anger may appear because of frustration. Individuals may even burst out angrily for no apparent reason. Being unable to figure out the world and cope with it may cause anxiety or nervousness. For example, patients may:

- Cry easily
- Repeat certain questions or actions over and over
- Talk non-stop and without clear purpose
- Experience delusions
- Be subject to restlessness, wandering and sleep disturbances
- May accuse others of stealing or cheating

LATE STAGE - Cognitive Changes

In the late stage of Alzheimer's, patients may be able to carry out activities, but lack the mental skills to do them with a clear purpose. Patients often become severely disoriented, losing touch with the world more and more. Late in the disease there is also likely to be a flattening of expression. You may not be able to tell if the person is feeling happy or sad, angry or frightened. You may wonder if the patient senses anything at all. Keep in mind, even the very impaired person may still be able to experience pleasure and emotional pain.

The patient, becoming more and more quiet and withdrawn, may show only the slightest response to others, or no response at all. Spouses and close family members often say, toward the end of the disease process, that the person who "used to be" no longer exists.

During this late stage of the disease, physical disability also may become extreme. The person may become bed-ridden and unable to control bladder and bowel functions. Skilled nursing care may be required in the final stages.

LATE STAGE - Behavioral Changes

The patient at this late stage may become even more involved in delusions. Examples of late stage delusional thinking include: believing the place where they reside is not their home; believing a thief is trying to get into the house; experiencing delusions of abandonment.

SUMMARY

It is important to remember that each person with Alzheimer's progresses differently. The stages described above are only guidelines. They may not necessarily occur in the order described. Additionally the progression of the mental and physical deterioration may be rapid or may proceed over a number of years. Each case is unique.

The role of the person caring for someone with Alzheimer's is constantly changing. Each stage of the illness brings its own special care problems. As some symptoms appear or old ones fade, the patient's needs change. A new set of problems and losses must be taken into account. In the early stages, the main problems may be forgetfulness and impairment of learning ability. This is the time to arrange for ongoing doctor's care and to plan for the future. Families need to talk with a lawyer and start a financial plan.

Safety is a major concern during the middle stage of the illness. The memory is failing and judgement is poor. The patient may wander or get into things around the home that pose a danger. The patient may need to be closely watched. A network of care arrangement is important.

In the final stages, nursing care may be needed. This is the point where most families must consider placement in a nursing home. This can be a difficult choice for some families. It is important to discuss it with people you can trust and who know what you are going through.

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

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1. New York State Office for the Aging. Caring For Alzheimer's Patients.
2. Zarit, Steven H., Orr, Nancy K., and Zarit, Judy M. The Hidden Victims of Alzheimer's Disease: Families Under Stress.

TEN A'S FOR ALZHEIMER'S CARE

Arguments are useless, and, in fact, make matters worse. Confusion, memory loss and frustration are making the person behave irrationally and you can't "argue" them out of it.

Allow as much freedom and independence as possible, while keeping safety and comfort in mind.

Actions help when verbal communication may fail. Help the patient by demonstrating what you mean, or sometimes, by starting them in the activity.

Assume that the person may understand and hear what you say even if they are confused. Do not say things to others in front of them as if they are deaf.

Appreciate good moments or good days, even though the person's ability is not going to remain that way.

Appropriate activities help patients pass the time meaningfully and productively and reduce agitation, boredom, daytime sleeping and depression.

Agitation can be alleviated when the caregiver remains calm, reassuring and respectful of the patient's feelings.

Adults with disabilities are still adults. Mental level is not always equal to social level.

Adapt the task to fit the ability of the patient. Breakdown the activity into separate steps, or simplify tasks by eliminating parts that could be frustrating.

Assessment is ongoing. What is safe and effective for now, may not be so at a later time. Keep watching and reevaluating.

Adapted from an article appearing in the Southern Tier Chapter Newsletter.

Hats off to...



Collaborative efforts...

The Northeast Texas Chapter of the Alzheimer's Association has joined a newly formed, city-wide coalition in Tyler. Participants include the University of Texas at Tyler, Tyler Junior College, the Tyler Independent School District, Association for Retarded Citizens, United Way, MHMR community center, and concerned relatives. The goal is to providing comprehensive day treatment and respite services for persons with disabilities.

The mission of the Coalition is "To develop a center of services for persons who are medically, mentally,

or physically handicapped and who require assisted services. These services will enable them and their families to maximize their life's experiences". The underlying belief is that groups which come together with common purpose can achieve greater community and financial support for their cause.

Current efforts focus on needs assessment and fund raising to purchase facilities which can serve a wide array of disabilities. To assist in this effort, a "Tour of Needs" is scheduled for November in which state, county, and city elected officials, local philanthropists, civic leaders, the media, and others will be taken on a guided tour of existing and proposed service sites, and will receive comprehensive education in the needs of the disabled in Tyler.

For more information, contact Marcia Bearden of the Northeast Texas Alzheimer's Association at 903-509-8323.

CAREGIVER CORNER

Mrs. Melida Coleman

"Caregiver." What an interesting word. It means what it says. Yet it also means more than a word can convey. It means "wife," "husband," "mother," "son," or "daughter." In its scope it is almost a generic word, but it should be found in the dictionary as a definition of "Love." I know what it is. I was a caregiver. My husband, Joe, had Alzheimer's for over sixteen years. He was bedridden for the last eight. Our doctors did not diagnose Alzheimer's until ten years ago.

Only by looking back into the past can I say that Alzheimer's started that long ago. Joe was forced into early retirement at age 62 because he was not doing his work as it was supposed to be done. He forgot to send in his report or make his calls on clients. In the years that followed, he would "forget" where he left his wallet or his money. He forgot how to tell time. I did not understand what was happening to Joe. Not until he underwent a number of medical examinations and tests was our doctor able to tell me that the final result of the progression of his disease would be like Alzheimer's.

"ALZHEIMER'S." That word had no meaning for me. I had read once that it was a disease that a Hollywood actress had. It was a word about which I knew nothing. I could not find any information in Laredo, so my sons who live in Austin attended meetings of the support group there and enrolled me as a member. Although I could not attend, I began getting newsletters with information about the disease and sources of further information on Alzheimer's.

"The Thirty-Six Hour Day," a book by Nancy L. Mace, and Peter V. Rabins, was a great help to me. I read it again and again, and I used it to find the answers to so many questions that I had. The book has been invaluable because it helped me to become aware of what was coming.

My husband was functional for a few years. He seemed to enjoy going out for long drives, eating at favorite places, and enjoying trips to our beach home in Port Aransas. But this did not last very long, because day by day Joe needed ever more attention.

There were numerous incidents that indicated to me that things were not going well. A flight to attend

the funeral of Joe's favorite aunt in Kentucky became a nightmare. He did not recognize many of his relatives. On a layover at one of the airports, he needed to go to the bathroom, and this problem created some anxious moments. I came to realize that our outings would have to be kept at a minimum.

It was becoming difficult for me to take care of his personal needs, so I hired a nurse to come in mornings to bathe him, take him for walks or just sit with him in the garden. Shortly after this, I hired a nurse assistant to care for Joe during the day while I worked. This was the beginning of getting people to help as caregivers, to work in shifts around the clock every day, seven days a week. I know that God answered my prayers because I was able to find caring people to look after Joe.

Today I look back over the past ten years, and I recognize this as one chapter in my life. Others will also have similar chapters inserted into the book of their lives. I have resolved that I want to help those who find themselves embarking on a similar journey with a loved one. Perhaps I can ease their anxiety, for the unknown can always create anxiety in us all. Maybe I can help them to cope with the long days and nights that lie ahead. I would say to them that faith must be an integral part of their lives. St. Paul says that to those who love God, all things work together for their good. To love God is to have faith in Him.

I have come to the end of the chapter. My Joe died on the first of August, 1993. He would have been 79 on the 21st. His was a peaceful death as he slipped from one life to the next. He was surrounded by family and friends who truly loved him. Of course, we want to remember him the way he was when he was hale and hearty. But I cannot, and we must not, forget what happened to him because of Alzheimer's.

I thank God that I was able to care for Joe at home. I have no regrets. I look forward to resuming the life that I gave up almost ten years ago. I will be dreaming new dreams, and looking forward always forward.

Mrs. Melida Coleman was appointed by Lt. Governor Bob Bullock to the Texas Council on Alzheimer's Disease and Related Disorders.

TASK FORCE ON SPECIAL CARE UNIT CERTIFICATION

Valerie Stephenson, CSW-ACP

In May 1992, the Texas Council on Alzheimer's Disease and Related Disorders appointed a Task Force to re-evaluate the voluntary certification standards for facilities serving individuals with Alzheimer's Disease and Related Disorders in Texas. The five member committee submitted a formal report to the Council in December 1992, following an extensive review of the literature regarding the issues surrounding Special Care Units (SCU) including development, marketing, quality assurance, clinical, certification and regulatory issues. The Task Force also conferred with national experts in Alzheimer's disease and long term care, gerontological professionals, nursing home providers and families of dementia residents.

In the final report, the Task Force concluded that the voluntary certification process in Texas for facilities with special care units for dementia residents does not meet the generally accepted goals of certification and regulation of special care units. These goals include:

- 1) Assurance that special care units are not established and operated solely for marketing purposes and that these units do, in fact, provide something "special" for their residents;
- 2) Protection of residents in special care units to assure they do not receive worse care than if they were not on a special unit;
- 3) Promotion of the establishment and/or evaluation of special care units.

Additionally, the Task Force recommended the implementation of Guidelines rather than certification standards for special care units, with facilities assuming the responsibility of providing to consumers and the public a "disclosure statement" which identifies the services, features and philosophy of care which distinguishes it as a special care unit. For a copy of the complete report, contact Veronda L. Durden at 1-800-242-3399.

Ms. Stephenson is Chair of the Texas Alzheimer's Council Task Force on Special Care Unit Certification.

NATIONAL WANDERING PROGRAM TO BE LAUNCHED

What would you do if a loved one suffering from Alzheimer's disease became disoriented, even in a familiar surrounding, and became lost? This is one of the most alarming, potentially life threatening and common behaviors accompanying Alzheimer's disease.

How can caregivers help prevent this tragedy from occurring? The Alzheimer's Association's Safe Return program, being launched this year, will help identify and relocate persons with Alzheimer's disease who become lost.

Individuals enrolling in Safe Return will receive an identification bracelet engraved with a 24 hour telephone number and personal identification number. The toll-free telephone number will not only allow caregivers to report missing Alzheimer persons to the authorities, but once found, will allow law enforcement officers and others to access important information regarding that person through a national database so they can be returned safely home.

Individuals interested in participating in Safe Return should call the local Alzheimer's Association Chapter, or the Texas Department of Health 1-800-242-3399.

Wandering

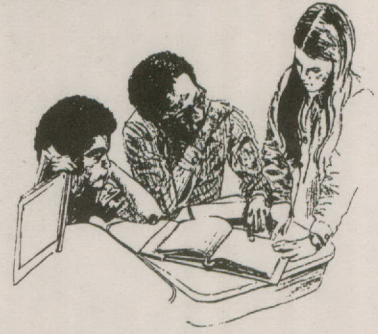
Wand'ring is a restless, tireless journey toward
the past
To haunts where old familiar habits roam,
To havens of calm normalcy where mem'ries last
and last,
A futile search for some place once called "home."

Wand'ring is escaping an accelerating wheel,
Strangeness and confusion all around,
Fleeting dumb frustration and disoriented feel,
From cryptic sights and cacophony sound.

Wanderers need someone near who cares and
understands,
Soothing words distract and reassure.
And just in case, some safety measures planned
by loved ones hands,
And vigilance to keep them all secure.

Jean Wood

Helpful New Resources



Alzheimer's Disease and Marriage. (1993) Lore K. Wright. Sage Publications, Inc. 2455 Teller Rd., Newbury Park, CA 91320-2218. (805)499-9774. Cost \$15.95 paperback or \$32.50 hard cover.

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Long-Term Care Quality Letter. (1993) Twice-monthly reports on total quality management and continuous quality improvement for nursing homes and related facilities. The Manisses Communications Group, Inc., P.O. Box 3357, Providence, RI 02906.

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