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# News

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**\*\*Program helps families learn to cope with and understand aging parents.**

DALLAS—When a person is diagnosed with Alzheimer's disease or another form of dementia, it can be a frightening experience for the family as well as the patient. Not only is it difficult to accept the diagnosis of a fatal disease, but also "it is traumatic for a grown child to watch his parent become as helpless as a baby," explains Dr. Helen West, associate professor of Gerontology Services Administration at The University of Texas Health Science Center at Dallas.

Helping the family cope with its role as caregiver was the focus of a recent "Health and Aging Workshop" sponsored in part by the Southwest Long Term Care Gerontology Center at UTHSCD.

Alzheimer's disease, called "primary degenerative dementia," is a slow progressive loss of mental functions due to some impairment of brain tissue and activity. It affects from five to 10 percent of the population over 65. In its earliest form, the irreversible illness is characterized by occasional confusion, mild memory loss, social withdrawal and easily triggered irritability. In its later stages, the patient suffers from total disorientation to time, place and person; wandering; inability to complete thoughts, recall words or name objects. Eventually, usually within five to seven years after diagnosis, there is complete loss of control of all voluntary and involuntary body functions, said Dr. Paul Chafetz, clinical psychologist at the health science center, during the workshop.

There is no cure or satisfactory treatment for Alzheimer's, and the cause is still unknown. Dr. Charles L. White, assistant professor of Pathology at the health science center, is studying the pathological changes in the brain of Alzheimer's patients. Explained West, the only way to diagnose the disease in a living patient is to rule out everything else -- benign tumors, communicating hydrocephalus (a form of hydrocephalus, in which there is an accumulation of cerebrospinal fluid in the brain), subdural hemotoma (blood clot), myxedema (a disorder of the thyroid gland), calcium deficiency, vitamin B<sub>12</sub> deficiency or neurosyphilis (syphilis affecting the nervous system). The only definitive diagnosis is through autopsy. During pathological examination, it has been found that there is an overabundance of aluminum in the brains of Alzheimer's patients, but it is still unclear whether this is a result of environmental or genetic influences.

When dementia is diagnosed, the family and the patient must find ways to deal with the dim prognosis: a steady, downhill functional decline in the patient's mental abilities.

It is crucial for the family to prepare for the tremendous emotional strain that will be placed on its members by caring for the patient, said West. Because the disease never stabilizes, the family is faced with a continuous onslaught of discouragements. Other family members' problems are ignored or discounted. The



patient might also have other illnesses related to age that require medical attention, involving additional time and cost. Since some of the most troublesome behaviors are wandering and incontinence, the patient needs 24-hour supervision. This, combined with the personality changes--many patients become obstinate, abusive and antagonistic--puts tremendous emotional and financial stress on the family.

In addition, the family may experience social isolation, embarrassment and a feeling of hopelessness--there is no cure, no treatment and nowhere else to turn for help or information.

Guilt, also, is a common emotion. The family may feel guilty for considering institutionalization; they may feel guilty for either imagined or real past transgressions--"If I hadn't treated him that way, he wouldn't be ill." The family might also feel guilty for becoming angry at the patient or thinking how much easier it would be if the patient died. As the Alzheimer's patient becomes unable to make any decision on his or her own, the family takes on the additional psychological burden of having to ultimately make all quality-of-life decisions.

It is important that the family realize that all these emotions are common and normal and that they need to seek a healthy outlet to rid themselves of guilt and frustrations, says West. One of the best ways is through support groups.

"A basic function of a support group is to explode all the myths concerning such dementias as Alzheimer's, while providing accurate information from current resources," she says. Emotional support and guidance, as well as serving as a qualified source of information are major roles of support groups.

Should the patient become too much to handle and be moved into a nursing home, the family experiences a new set of emotions. The overwhelming feelings of guilt and frustration are often taken out on the nursing home staff. Often, said West, the family uses the staff as a scapegoat for all their negative emotions. They might become obnoxiously supervisory and intrusive. Well-adjusted families relieve their feelings of guilt by making friends with the staff and being helpful not only with their own relative but with other patients and families as well. They might form family activities, or trade off visiting time with other patients to alleviate some of the routine. To cope in the healthiest way, they must integrate themselves into the total care but at the same time relinquish the responsibility for 24-hour supervision.

For information on caregiving, support groups or starting a support group of your own, contact West at the Southwest Long Term Care Gerontology Center located at the health science center, 688-2820, or the local chapter of the National Association for Alzheimer's Disease, 948-7973.

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