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## **Case Study: Preventing the Unnecessary Losses of Alzheimer's Disease**

by Lin E. Noyes, RN, MSN

Lin E. Noyes is a charter member of the Alzheimer's Association, Northern Virginia Chapter and was a member of the Public Policy Committee of the National Alzheimer's Association from 1989 to 1994. From 1986 to 1994 she was also a member of the Virginia Governor's Commission on Alzheimer's Disease and Related Disorders, which worked to improve the state's policies and laws regarding people with Alzheimer's Disease and other dementias and their family caregivers.

Currently, Lin is the Director of the Family Respite Center, which provides day care and other services for people with dementia and is a Ph.D. candidate at George Mason University in Administration, Health Policy, and Ethics in the College of Nursing.

### **Educational Objectives**

1. To state the importance of early detection and diagnosis of Alzheimer's disease.
2. To describe common concerns of people in the early stages of Alzheimer's disease.
3. To describe interventions to help people who have recently been diagnosed with Alzheimer's disease or other dementias.

### **Case Study**

Pam K. at 74 years old delighted in telling me about running the Native American Art Gallery and working "on the hill" with legislators and lobbyists. She has had a full life and is now happily married to her third husband. She had driven herself across town this day to ask for my help. She told me that she had been recently diagnosed with Alzheimer's disease and wanted to join a support group but couldn't find one. She had heard of the Family Respite Center's work with people in the later stages of dementia and now wanted us to help her. She was tearful and had some trouble speaking fluently, but was more than able to carry on a meaningful conversation. She was quite persuasive in her requests for help. The experience of meeting someone with mild dementia had a profound effect on me. I soon learned that her problems and concerns were more similar to my own than they were similar to people in the middle stages of Alzheimer's. Our response to Pam, and the other people we began to meet with mild dementia, was to start an *Early Intervention Program*. Pam is the co-facilitator of the early stage support group. Health education sessions are given once a month after the support group. We have developed a special dinner and discussion group for couples when one spouse has Alzheimer's disease. It meets once a month in the evening. After almost one year, there are 5-8 people at each support group, up to 20 attending the health education talks, and as many as 10 couples attending the monthly dinners. The response, while slow in the beginning, is now good as the word travels that you can do something about Alzheimer's disease!

### **Background**

Alzheimer's disease (A.D.) is a progressive neurologic disorder; the most common cause of dementia among older people (NIA, 1996). It is considered that Alzheimer's disease will be the number one public

health concern of the 21st century, since its incidence increases with age and those over 85 are the most rapidly increasing segment of the U.S. population.

The good news is that A.D, once shrouded in myths and lack of understanding, is now more easily recognized and diagnosed. In addition, research is beginning to yield some treatments for the symptoms of Alzheimer's disease. This article will describe the role of the health professional in helping people at risk for a dementing illness and those in the early stages of their illness.

Fifteen years ago Alzheimer's disease was more difficult to diagnose in the early stages and considered impossible to "treat". In fact, health care professionals rarely saw people with A.D. until they had lost the ability to care for themselves or they exhibited difficult behavioral problems. Looking back on those days one can see that health care professionals treated A.D. in the middle stage and had no specific treatments for people at the beginning or the end of their illness.

Today, because the health community and the public have a greater knowledge of the signs and symptoms of Alzheimer's disease, people in the very early stages of Alzheimer's are seeking a diagnosis when they are still able to contemplate what their future will be like without memory and are still able to care for themselves. As health professionals, we have an obligation to help people learn about the signs and symptoms of this disease and advocate for early diagnosis and treatment.

### **Recognition of Symptoms and Diagnosis**

Many more people, older people especially, worry that every occasion of forgetfulness is a sure sign that they are "coming down with Alzheimer's disease." In fact, the fear of having Alzheimer's may keep people who are experiencing memory loss symptoms from seeking help. This is unfortunate since some of the causes of cognitive changes are treatable if diagnosed early.

Health professionals must recognize people who are at risk, monitor their mental status and advocate for diagnosis if symptoms of dementia become apparent.

Yale (1994), in one of the few books about the early stages of dementia, describes people who are at risk and/or who may be in the early stages as those who may have trouble "word finding" or "way finding," or have problems with spatial perceptions or memory problems. These people need little help with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) and probably still have the capacity for introspection and comprehension. New pharmacological interventions appear to have their greatest success in these preliminary phases, and "reversible dementias" are more successfully treated before symptoms become more pronounced. Therefore, health professionals cannot wait to see a person failing with ADLs before they advocate for diagnosis.

## **Helping People in the Early Stages**

If an Alzheimer's type dementia is diagnosed by a neurologist after a thorough diagnostic work up, there are many things that can be done to help the person, especially in the early stages.

### Pharmacological Interventions

Aricept (donepezil hydrochloride) is given to people in the early stages of Alzheimer's to increase the concentration of acetylcholine in the brain, thereby improving cognitive functioning. This drug is an improvement over Cognex (tacrine hydrochloride), the first drug aimed at treating the symptoms of A.D., since Aricept is only taken once a day and does not have the high risk of liver toxicity that Cognex has. It is a treatment, not a cure, and is most effective in the early stages. People generally experience greater word fluency and better recall when taking Aricept. It may also have an effect on the diagnosed person's sense of well being, since in the early stages he or she will still be cognizant that something is being done. The improvements vary from person to person, and are modest at best, but definitely worth considering, unless there are good medical reasons not to try the medicine.

Other drugs that physicians may consider prescribing are Vitamin E, Estrogen, and Ibuprofen since all have shown some efficacy in research studies. Since drug treatment options are relatively new, finding a doctor who keeps current with the research findings in this area may provide the greatest help to the diagnosed person.

### Health Education

Alzheimer's disease is a chronic, debilitating illness. Just like persons with other chronic debilitating illnesses, people with A.D. feel that they have more control over their lives when they have information about the disease, treatment options, and research efforts taking place on their behalf. As with many other illnesses, educating people about A.D. and separating facts from fiction can help them come to terms with what is happening to them. Knowledge empowers people, even if there is little they can do to change their situation. While there have been a few widely publicized cases of assisted suicide by people in the early stages of Alzheimer's, there is no research to support the notion of increased incidence of suicide in persons who know that they have the disease. People need to know that having Alzheimer's disease today is "different" from when their grandmothers had it; treatments and care are much better and more humane, and research is moving rapidly toward more effective treatments.

### Support for the Diagnosed Person

While support groups for family caregivers have been in existence in Virginia for almost twenty years, community support groups for people with the diagnosis are very new and very helpful. One person diagnosed with A.D. said at the end of a support group, "this group gives me hope." Another lady who was looking forward to attending her first support group meeting said, "I wonder what the other people in the group will look like." The message from both of these comments is that people feel better knowing that other "normal" people are in the same situation and benefit from coming together. Support groups for people with mild dementia may be difficult to get started until the awareness of the benefit of the group increases but are definitely worth the effort and perseverance of the group facilitator.

### Cognitive Exercises

While there is not an abundance of research data to support it, common sense supports the idea that exercising memory and other cognitive skills keeps healthy brain cells functioning longer. Quayhagen, Quayhagen, Corbeil, Roth and Rodgers (1995) reported temporary improvements in cognitive and behavioral performance with a regimented program of cognitive stimulation in people with mild memory impairment. Snowden's (1997) preliminary findings in the "The Nun's Study" also supports the "use it or lose it" theory of encouraging cognitive stimulation and exercising the brain.

To summarize, people with cognitive changes should be identified, diagnosed and treated. If an Alzheimer's type illness is diagnosed, treatment options include medications, education, support, and cognitive stimulation.

### Study Questions

1. Why is an early diagnosis of Alzheimer's disease important?
2. What kind of support is available for those diagnosed with Alzheimer's disease?

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