

# What is AD?

*This pamphlet is part of a series on dementia-related diseases. This series was prepared by Kenneth Hepburn, Ph.D., Geriatric Research, Education and Clinical Center (GRECC) of the Department of Veterans Affairs Medical Center, Minneapolis, Minnesota.*

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Alzheimer's disease is a steadily is a steadily worsening disorder of the brain's nerve cells. Parts of the patient's brain are destroyed by the disease, causing "dementia," or impaired brain function. Such damage causes a wide variety of problems for the Alzheimer victim. The early symptom of the disease is faulty thinking. The impairment shows up in a number of ways for instance: memory loss, problems coming up with words and having a hard time concentrating. Depending on the length of time the disease has been present and the patient's age, other changes may show up in the way the patient acts and reacts. In its later stages, the disease causes the patient to lose control of physical functions and results in total disability and eventual death.

People may develop Alzheimer's disease symptoms at any time from about age forty, although most commonly the disease begins in the mid-sixties or later. Generally, the disease progresses faster for younger people, **but every person reacts differently**. The disease does not always progress in a steady fashion. There may be fairly long periods when the symptoms stay about the same, and then they may suddenly get worse over a rather short period.

Regardless of the patient's age at the time of onset, Alzheimer's disease progresses without "remission" or improvement. Alzheimer's disease is a terminal illness. The course of the disease may span a few years or as many as fifteen or twenty, again depending on the individual person. On average, though, the disease generally runs its course in about eight years.

## **Causes and treatment of the disease**

Contrary to popular belief, Alzheimer's and other dementing diseases are not caused simply by old age itself. In fact, most older people are never affected. A range of diseases-of which Alzheimer's is the most common-cause dementia in about five percent of Americans over the age of sixty-five. Dementia is most common among very old persons. Roughly twenty percent of those over eighty-five years of age will be afflicted. Somewhere between one-half and two thirds of all the people afflicted with dementing illness are victims of Alzheimer's disease. With a growing elderly population the number of cases of Alzheimer's disease and related disorders may be expected to increase.

Although promising research is underway, at this time no one has yet discovered the cause or causes of Alzheimer's disease. More importantly, no treatment yet exists that can change the course of the disease. Health care and management techniques have been developed, however, for many of the more troublesome symptoms. Help is also available for Alzheimer's patients and their families through community services and support groups such as the Alzheimer's Disease and Related Disorders Association (ADRDA). For information about Alzheimer's disease and the location of local ADRDA chapters, you can call, toll free, 1-800-621-0379.

## **The course of the disease**

Alzheimer's disease is often described in terms of early, middle and late stages. These are general rather than precise terms. Each person is unique. The symptoms that occur, when they occur and how long they last will vary in each case.

### **Early stage:**

Early in the disease, **short-term memory loss** occurs. Other problems go along with this:

- *Being unusually forgetful;*
- *Having a hard time concentrating;*
- *Having a hard time coming up with the right word;*
- *Making poor choices or showing bad judgment.*

During this stage, subtle changes in personality may occur. The person may also not be able to adapt to changes in old routines.

Memory loss in itself is not a sign of Alzheimer's disease. Most people normally have some memory loss as they age. In Alzheimer's disease, the problem will worsen steadily.

Although symptoms may seem to come on quite quickly, the problem often builds very slowly. Many times the symptoms are first noticed after the person has been under some strain. A change of homes, an illness, or a trip can overtax a person in the early stage of the disorder.

Depression is one of the more common symptoms in the early stage of the disease. The signs of depression may include seeming sadder, quieter or more negative than usual, sleeping too much or too little, losing an unusual amount of weight, drinking more than usual or not seeming aware of or interested in things.

Perhaps the ill person and those around him or her will just have the feeling that "something is not right." The forgetful person may also feel frightened, ashamed or just plain bewildered by the changes. The person may try, often very successfully, to hide the problem (by writing out detailed reminders on how to do routine activities, for instance). As a result, even those people closest to the impaired person may need a fairly long period of time, even years, to realize that something is really wrong.

As soon as the problem is noticed, however, a doctor who knows about dementia should see the forgetful person. A firm diagnosis of Alzheimer's disease is not yet possible in this stage of the disease. Still, an early exam permits the doctor a basis for comparing later symptoms. (The doctor will watch for signs of a worsening trend in the symptoms.)

Keep in mind, too, that other conditions, which do respond to treatment, can look like Alzheimer's disease. The doctor will want to rule out (or treat) these other problems as early as possible. Depression, for instance, can worsen the symptoms of a person with Alzheimer's disease or cause similar symptoms in otherwise healthy people. The

symptoms of depression can often be improved by medical care and should always be treated.

In this stage of the illness, the impaired person may still be able to do most things with a certain amount of help. Hard as it may be, this is also the time to plan for the future when the patient's disability will become more severe.

### **Middle stage**

The middle stage of Alzheimer's disease is characterized by **more and more severe memory loss**. The person is often not able to recognize family and friends. The person's judgment gets worse and worse. Sometimes the patient has delusions. He or she is less and less able to learn or adapt to new situations. The person may also have striking personality changes, become very active and lose language abilities.

The impaired person may become unable to remember even basic safety rules. Thus daily activities such as cooking, driving or using appliances may pose a danger. The impaired person may also be subject to restlessness, wandering and sleep disturbances. You may have to watch over the person closely. You may have to keep the person from doing things he or she is used to. This part of caregiving can be very hard.

The patient's extreme shifts in mood can pose other problems for the caregiver. Sudden bursts of anger or fits of extreme worry may occur. The person may accuse you or others of doing bad things to him or her, like stealing or cheating. All this makes daily activities and care more difficult. There appears to be no way to predict if or when these changes will occur or how long they will last if they do occur. Also, even if a person's mood changes in one way, this does not mean that other difficult mood changes will also occur.

Anger may appear because the person is frustrated. The disease reduces the person's ability to perform all adult activities so that the person, increasingly, can neither understand nor make himself or herself understood. Alzheimer's patients may even burst out angrily with no apparent explanation.

Being no longer able to figure out the world and cope with it may cause the person to be anxious or nervous. Patients may cry easily, repeat certain questions or actions over and over, or walk non-stop and without clear purpose.

If impaired people become very suspicious, they may accuse others of plotting against them or of trying to steal from them. They may go to great lengths to guard against imagined threats. Sometimes they may even strike out against their caregivers, mistaking care efforts for attempted assaults.

Even in this stage, the impaired person can keep on enjoying many activities. To do this, care has to be managed well, and any other health or emotional problems have to be treated promptly. To assure this goal, you will need to keep increasing the network of people and services that help you to provide care. The task of caregiving may well expand beyond the ability of any one person.

### **Late stage**

In the late stage of Alzheimer's disease, patients may be able to carry out activities, but they lack the mental skills to do them with a clear purpose. Patients often become **severely disoriented**, losing touch with the world more and more. The impaired person may become ever more involved in delusions. (The person will believe in the delusions, but they will have no basis in fact.)

Late in the disease there is also likely to be a **flattening of expression**. You may not be able to tell whether the person is feeling happy or sad, angry or frightened. You may wonder if the person is sensing anything at all. Even the very impaired person may still be able to experience pleasure and pain.

Patients become more and more quiet and withdrawn. They 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 stage of the disease, **physical disability** also may become extreme. The person may become bedridden and incontinent (not able to control bladder and bowel functions). Skilled nursing care may be required in the final stages before death.

Alzheimer's disease is the fourth leading cause of death among Americans over the age of sixty-five. Still, people do not, as a rule, die directly from the disease. The more usual direct causes of death are infections, physical disorders or accidents such as choking on food.

## **Treatment and management**

No known treatment cures or slows down the overall progress of Alzheimer's disease. Be wary of ads you may find that promise so-called 'treatments' for Alzheimer's disease. There are two things you should know about these treatments. First, **no proof exists that these treatments work**. Special diets, 'chelation therapy,' and 'mega-vitamin therapy' do not alter or reverse the course of the disease. Second, **these treatments are expensive**, and some people will offer to provide such therapy as a way to profit from the misfortunes of others.

Although no cure exists for Alzheimer's disease itself, specific treatments do exist for some problems that occur along with the disease. Drug treatment may relieve symptoms of depression or anxiety or undue aggressiveness. Infections, which worsen the Alzheimer's symptoms, can often be cured. Keep in mind, too, that other conditions that do respond to treatment can look like Alzheimer's disease. Even without hope of a full cure, the care goal remains of ensuring the greatest possible safety and comfort for the Alzheimer's patient.

For all of these reasons, your health care team needs to continue careful treatment of the patient. You, as caregiver, need to continue reporting any changes in the patient's symptoms or behavior. You and the health care team need to work together to set up a working program to manage the patient's care. A good care management program should help you anticipate and even avoid many care problems.

A good care management program must be suited to **your** needs and strengths as well as those of the person in your care. The course of the disease may span many years and bring many changes for the impaired person and for you. These changes may be hard and painful, even if you know in advance that they are coming. In some families with many helping partners, family members may be able to care for the person with Alzheimer's disease over many years until the person dies. In other families, ongoing daily care becomes too great a burden or the family cannot provide the care that is needed.

You will need many resources to help you. Do not wait to look for help until you are exhausted, your health has suffered or you cannot cope any longer. Outside resources for patient care do exist, although often fewer than needed. Begin early to plan for the future and to set up a network of other care arrangements for your impaired family member.

One final point: you will come to rely on the health care team and the team will come to rely on you. For this reason it is crucial that you find a doctor or a team that you trust and that you feel really helped by. It is not always easy to find a doctor or a team that knows about Alzheimer's disease and that will work closely with you and your family. If the doctor you have always used doesn't know about the disease or doesn't seem to want to work closely with you as you care for the patient, think about finding another doctor. Ask others who provide care how they have solved this problem. The Alzheimer's Disease and Related Disorders Association can be helpful.

## **Help for the caregiver**

**This is the** first of a series of pamphlets designed to assist you as a caregiver for a person with Alzheimer's disease or a related disorder. The series offers you facts and ideas about the disease itself and the caregiving role. It offers ideas for solving care problems that come up in the course of caregiving. The series stresses the need for planning for the future with care and frankness. The series also stresses how crucial your caregiving role is, how much of a strain it can put on you and how important it is that you care for yourself.

Key in all of these things will be the following:

- *Assess the situation and care needs of the impaired person.*
- *Assess your own situation as a provider of care.*
- *Learn to work in partnership with your health care team.*
- *Develop a network of other people and organizations that can help you as you learn to care for the impaired person.*
- *Develop plans and techniques to ensure good care for the patient while maintaining your own health, both now and in the future.*

The pamphlets should be used along with the personal advice of your health care team and other advisors. Reading the pamphlets should help you observe the patient in your care more accurately, express your needs more clearly and better understand and carry out treatment or care management and planning suggestions.

Further suggestions for your health care professional

Your doctor or nurse can recommend specific parts of the series, which might be helpful in your case. Each pamphlet includes a list of further recommended readings on the particular subject in question. Use the pamphlets as guides, and discuss any questions or reactions you may have with your doctor or nurse. Let them know what is helpful, what doesn't work in your case and what ideas you have come up with on your own. Such discussion and sharing of ideas can help all of others with similar problems.