

ALZHEIMER'S IDENTIFICATION

Carry identification with you that indicates you have an Alzheimer's patient in your care. The national Alzheimer's Association has an excellent ID program for you and the patient. Arrange for someone else to fill in for you before an emergency occurs.

Personal Notes:

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A BRIEF GLOSSARY

Dementia - Is not a disease. Is a group of symptoms involving decline in an individual's intellectual functioning, severe enough that it interferes with daily activities.

Senility - the old name for dementia. Once thought to be a normal part of growing older, it is now known to be caused by a disease.

Paranoia - an excessive or irrational distrust and suspiciousness of others. Fearfulness.

Further reading and resources:

When Memory Fails, Allen Jack Edwards, Ph.D., Plenum Press, 1994

When Your Loved One Has Alzheimer's, David L. Carroll, Harper & Row, 1989

Caring for the CareGiver, sponsored by Parke-Davis, 1994

Grandpa Doesn't Know It's Me, Human Sciences Press, Inc., 1986

The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss Later in Life, Nancy L. Mace and Peter V. Rabins, MD, John Hopkins Press, 1991.

Alzheimer's Association (800) 272-3900
National Institute of Health - Aging (301) 496-1752
National Institute of Mental Health (301) 443-3513
Alzheimer's Disease Education and Referral Center (800) 438-4380
American Association of Retired Persons (800) 424-3410

UNDERSTANDING



ALZHEIMER'S DISEASE

You've just been told that a loved one is suffering from Alzheimer's Disease or AD. You may have suspected it but were hoping that the changes you've seen in your loved one would be due to some other problem, something that was temporary. You need some facts now to help you understand and put things in perspective....

Is Alzheimer's Disease a new illness?

Alzheimer's was first diagnosed in 1907 by a German physician Alois Alzheimer. For many decades the condition was thought to be rare. Now that modern medicine is helping people to live longer, we know Alzheimer's Disease isn't rare.

What is Alzheimer's Disease?

At this time it is an incurable disease that affects the brain, specifically those areas controlling short-term memory. It is one of the diseases that result in dementia. It afflicts rich and poor, male and female. In the U.S., it affects 4 million people, with 250,000 new cases each year.

Is Alzheimer's a disease of the elderly?

Alzheimer's affects 1 out of 8 adults over the age of 60. Although most people stricken with Alzheimer's show no signs of the disease until the age of 75, there have been a few cases in which Alzheimer's affects younger adults.

What causes Alzheimer's Disease?

No cause has yet been found. There is a possibility of a genetic factor and much research is being directed toward that area. Chronic stress *may* contribute to its onset.

What are the early symptoms?

The disease robs people of their memory. At first, a victim forgets little things, such as where they left their glasses or that they were cooking something on the stove, causing the food to burn. Or they forget to write a check for the phone bill and just put the bill away in a drawer. They may injure themselves because they don't remember they have a lit cigarette in their hand. Later they may lose their memory for names of objects, as well as people. Or they may forget how to walk or how to dress themselves.

The disease causes confusion, poor judgment, changes in emotional behavior and loss of coordination. The patient must be prevented from driving a vehicle or operating power tools.

Do the symptoms get worse?

The middle stage has a noticeable increase in the changes in emotional behavior. A greater lack of patience, wandering around, striking out physically or verbally, and paranoia are seen. The patient begins hiding things. It's

likely that slower understanding and speech, increasingly hostile frustration behavior, and poor social skills may develop. The patient will not want help.

The advanced stage sometimes causes patients to lose control of bodily functions. In addition they may begin to hallucinate and/or become abusive or distant.

In *the final stage* of the disease patients generally lose all coordination and all memory. They do not recognize anyone or remember anything. Their suffering is actually now over and all that can be done is to keep them reasonably comfortable.

Can the symptoms be treated?

Unfortunately, there is no cure, as well as no prevention, for the disease. It was hoped that a drug called tacrine would help the thinking processes of Alzheimer's patients. However, results have been rather discouraging so far, since the condition of some patients has worsened after treatment with the drug.

How do we really know it's Alzheimer's Disease?

Physicians can only diagnose AD after eliminating all the other possibilities. Even so, confirmation can only come from an autopsy. Then, the abnormal deposits, or plaques, and tangled bundles of

nerve fibers developed by the disease, can be seen in the brain.

WHAT'S INVOLVED WITH HOME CARE

Physical care

Above all, you will need patience. Over time your loved one will need more help with the daily demands of life. But bathing, grooming, toileting, dressing and clothing care can be continued by the patient for some time, with a little assistance and prompting.

Maintain their dignity by allowing them to do as much as possible for themselves. Do not simply take over in the early stages, even if that would be faster and easier for you.

If the patient seems to have little appetite, try to serve favorite foods, using lightweight, brightly colored table settings to make everything easier to distinguish. Try for nutritional balance more than variety. Spoons can be easier to use than forks and, if thought of ahead of time, finger foods can be most enticing of all.

Communication

Because of the several stages of memory loss, your patient will try to fill in the words he or she can't remember, often by making up new words.

The patient may ramble and have a short attention span. You'll need to "keep it short" yourself, so they can follow what you're saying. Never speak harshly, and try your best to avoid arguing. Both will confuse or upset him or her. Don't use baby talk.

Reminders printed in large letters and put up around the house are reassuring. Items and drawers can also be labeled. Point to things while naming them.

Delusions and hallucinations may occur in the later stages, but they may also be due to a different medical condition. Tell the doctor so he can check into it.

CARING FOR YOURSELF

Don't try to go it alone! You'll learn that watching over an Alzheimer's patient quickly becomes a 24-hour a day responsibility. You must take time out for you. Don't be a martyr.

Make sure everyone in the family helps you in some way, either physically or financially, so you can preserve your health. That means family meetings to decide on sharing the load. And don't let anyone beg off because "it's not my problem." They must see that you need their help.

While the patient is at home, go for a walk around the neighborhood a couple of times a day, even if it's for ten minutes. If

possible, sometimes take the patient with you on longer walks. Make quick trips to the grocery store, alone. Put the patient in a wheelchair and go to the shopping mall. There's still a world out there.

Don't forget to call your friends and write letters. Read while the patient is napping. Put humorous videotapes in the VCR but keep TV news onslaught to a minimum.

Try a support group or two. If you find one where everyone talks but you don't want to, stay quiet anyway. If you don't feel very comfortable, try another group.

WHEN TO BRING IN HELP

You must get out of the house by yourself for a few hours two or three times a week. Also, once a month, try to find someone to come in all day, or even overnight if you feel the need for a longer break. This can be a volunteer or paid companion, or a licensed nurse's aide, depending on the patient's condition. You may want to hire a licensed professional on a steady basis. The patient's doctor can best advise the level of expertise that's needed.

Start early locating long term care facilities that will accept advanced or final stage Alzheimer's patients, and the means to pay for the care. They may not be needed, but if they are, you don't want to be making a decision in a hurry.

WHERE TO FIND HELP

Start with the phone book and other people you may know who have been through this.

Find charitable and religious organizations who might be able to offer advice and help about respite care, as it's called.

Call public agencies and nurses groups, too.

