

## Health Guide

[HEALTH](#) > [TIMES HEALTH GUIDE](#) > [A](#) > [ALZHEIMER'S DISEASE](#) > IN-DEPTH REPORT: STAGES

# Alzheimer's Disease

## Stages

The lifespan of patients with Alzheimer's is generally reduced, although a patient may live anywhere from 3 - 20 years after diagnosis. The final phase of the disease may last from a few months to several years, during which time the patient becomes increasingly immobile and dysfunctional. Caregivers should understand the phases of this illness in order to help determine their own capacities for dealing with this painfully sad disease.

### HOME TREATMENT IN EARLY STAGES

*Telling the Patient.* Often doctors will not tell patients that they have Alzheimer's. If a patient expresses a need to know the truth, it should be disclosed. Both the caregiver and the patient can then begin to address issues that can be controlled, such as access to support groups and drug research.

*Mood and Emotional Behavior.* Patients display abrupt mood swings, and many become aggressive and angry. Some of this erratic behavior is caused by chemical changes in the brain. But it may also be due to the experience of losing knowledge and understanding of one's surroundings, causing fear and frustration that patients can no longer express verbally.

The following recommendations for caregivers may help soothe patients and avoid agitation:

- Keep environmental distractions and noise at a minimum if possible. (Even normal noises, such as people talking outside a room, may seem threatening and trigger agitation or aggression.)
- Speak clearly. Most experts recommend speaking slowly to a patient with Alzheimer's disease, but some caregivers report that patients respond better to clear, quickly spoken, short sentences that they can more easily remember.
- Use a combination of facial expressions, voice tones, and words for communicating emotions. (One study suggested that patients may have difficulty in recognizing the meaning of facial expressions, particularly those signaling sadness, surprise, and disgust.)
- Limit choices (such as clothing selection).
- Offer diversions, such as a snack or car ride, if the patient starts shouting or exhibiting other disruptive behavior.
- Simply touching and talking may also help.
- Maintain as natural an attitude as possible. Patients with Alzheimer's disease can be highly sensitive to the caregiver's underlying emotions and react negatively to patronization or signals of anger and frustration.
- Showing movies or videos of family members and events from the patient's past may be comforting.

Although much attention is given to the negative emotions of patients with Alzheimer's disease, some patients become extremely gentle, retaining an ability to laugh at themselves or appreciate simple visual jokes even after their verbal abilities have disappeared. Some patients may seem to be in a drug-like or "mystical" state, focusing on the present experience as their past and future slip away. Encouraging and even enjoying such states may bring some comfort to a caregiver.

There is no single Alzheimer's personality, just as there is no single human personality. All patients must be treated as the individuals they continue to be, even after their social self has vanished.

*Appearance and Cleanliness.* For the caregiver, grooming the patient may be an alienating experience. For one thing, many patients resist bathing or taking a shower. Some spouses find that showering with their afflicted mate can solve the problem for a while. Often patients with Alzheimer's disease lose their sense of color and design and will put on odd or mismatched clothing. It is important to maintain a sense of humor and perspective and to learn which battles are worth fighting and which ones are best abandoned.

*Driving.* As soon as Alzheimer's is diagnosed, the patient should be prevented from driving. One study found that more than half of elderly people involved in fatal accidents had some degree of neurologic damage.

*Wandering.* A potentially dangerous trait is the patient's tendency to wander. At the point the patient develops this tendency, many caregivers feel it is time to seek out nursing homes or other protective institutions for their loved ones. For those who remain at home, the following precautions are recommended:

- Locks should be installed *outside* the door, which the caregiver can open, but the patient cannot.
- Alarms may be installed at exits.
- A daily exercise program should be implemented, which may help tire the patient. One study showed that walking 30 minutes, three times a day, also improved communication.
- The caregiver should contact organizations, such as Alzheimer's Association or Medic Alert, for identification supplies and procedures that help locate patients who wander away from home and become lost.
- Some experts are discussing the benefits versus the ethics of electronic tagging, which would emit a radio signal or alarm that allows the patient to be tracked using a detector.

*Speech Problems.* Some evidence suggests that speech therapy combined with Alzheimer's disease medications may be helpful for maintaining verbal skills patients with mild symptoms.

*Sexuality.* In many cases, the patient becomes uninhibited sexually. At the same time, the patient's physical deterioration and receding capacity to recognize the spouse as a known and loved individual can make sexual activity unattractive for the caregiving spouse. Other patients may lose interest in sex. If sexual issues are a problem, they should be discussed openly with the doctor. Ways should be found to maintain non-sexual physical affection that can bring comfort to both the patient and the spouse.

## HOME TREATMENT DURING LATER STAGES

Patients with Alzheimer's disease need 24-hour a day attention. Even if the caregiver has the resources to keep the patient at home during later stages of the disease, outside help is still essential. If available, home visits by a health profession can have a favorable impact on survival and delay the need for a nursing home. Medicare now covers many Alzheimer's services, and patients should be able to stay at home longer than previously.

*Incontinence.* A patient's incontinence is generally devastating to the caregiver and a primary reason why many caregivers decide to seek nursing home placement when the patient reaches this stage. When the patient first shows signs of incontinence, the doctor should make sure that it is not caused by an infection. Urinary incontinence may be controlled for some time by trying to monitor times of liquid intake, feeding, and urinating. Once a schedule has been established, the caregiver may be able to anticipate incontinent episodes and get the patient to the toilet before they occur.

*Immobility and Pain.* As the disease progresses, patients become immobile, literally forgetting how to move. Eventually, they become almost entirely wheelchair-bound or bedridden. Bedsores can be a major problem. Sheets must be kept clean, dry, and free of food. The patient's skin should be washed frequently, gently blotted thoroughly dry, and moisturizers applied. The patient should be moved every 2 hours and the feet kept raised with pillows or pads. Exercises should be administered to the legs and arms to keep them flexible.

*Dehydration.* Dehydration can become a problem. It is essential to encourage fluid intake equal to 8 glasses of water daily. Coffee and tea are diuretics and will deplete fluid.

*Eating Problems.* Weight loss and the gradual inability to swallow are two major related problems in late-stage Alzheimer's and are associated with an increased risk of death. Weight gain, however, is linked to a lower risk of dying. The patient can be fed through a feeding syringe, or the caregiver can encourage chewing action by pushing gently on the bottom of the patient's chin and on the lips. The caregiver should offer the patient foods of different consistency and flavor. Because choking is a danger, the caregiver should learn to administer the Heimlich maneuver, which may be taught by the local Red Cross. In very late stages, some caregivers choose feeding tubes for the patient. They should be aware that feeding tubes have no measurable impact on survival.

## CARE FOR THE CAREGIVER

About 80% of patients with Alzheimer's disease are cared for by family members, who often lack adequate support, finances, or training for this difficult job. Few diseases disrupt patients and their families so completely or for so long a period of time as Alzheimer's. The patient's family endures two separate losses and grieves twice:

- First, they must grieve for the ongoing disappearance of the personality they recognize. Dealing with the patient throughout the course of the disease is like Alice's fall down the rabbit hole into Wonderland. No sooner has the caregiver grappled with one set of problems, when the patient's further deterioration creates new and more intractable ones.
- Finally, the caregiver must grieve the actual death of the person.

Often, caregivers themselves begin to show signs of mental disorder or ill health. Depression, empathy, exhaustion, guilt, and anger can play havoc with even a healthy individual faced with the care of a loved one suffering from Alzheimer's.

Fortunately, research shows that intensive support services can greatly improve caretakers' quality of life and make it easier for them to continue caring for patients in their homes. In a 2006 study, caregivers who received individual and family counseling, telephone counseling, support groups, and stress management and problem-solving techniques reported reduced rates of depression and improved self-confidence compared with those who received only written educational materials. Another 2006 study indicated that improving caregivers' access to counseling and support services can help delay nursing home placement of patients. National and local Alzheimer's associations can provide important support and other services.

### **NURSING HOMES AND OTHER OUTSIDE SERVICES**

A point comes when the most devoted caregiver will probably need to institutionalize the patient. That point is determined not only by the caregiver's emotional endurance, but also by their physical strength and stamina, as a patient typically takes on the random, undisciplined behavior of a very young child. Financial considerations in finding a nursing home are often paramount, but the kind of care is equally important. Although fully half of all nursing home patients suffer from Alzheimer's, not all nursing homes have programs specifically designed for them. Some institutions may claim that they do, but often they simply group patients together without offering any special programs. If a caregiver manages to find a facility that offers good services, it may be located far from home, making visits difficult. The caregiver must then decide whether superior care at a distant institution is worth seeing the patient less frequently. When the patient's illness becomes terminal, a hospice program may be another option.

### **TWELVE STEPS FOR CAREGIVERS**

1. Although I cannot control the disease process, I need to remember I can control many aspects of how it affects my relative.
2. I need to take care of myself so that I can continue doing the things that are most important.
3. I need to simplify my lifestyle so that my time and energy are available for things that are really important at this time.
4. I need to cultivate the gift of allowing others to help me, because caring for my relative is too big a job to be done by one person.
5. I need to take one day at a time rather than worry about what may or may not happen in the future.
6. I need to structure my day because a consistent schedule makes life easier for me and my relative.
7. I need to have a sense of humor because laughter helps to put things in a more positive perspective.

8. I need to remember that my relative is not being difficult on purpose; rather their behavior and emotions are distorted by the illness.

9. I need to focus on and enjoy what my relative can still do rather than constantly lament over what is gone.

10. I need to increasingly depend upon other relationships for love and support.

11. I need to frequently remind myself that I am doing the best that I can at this very moment.

12. I need to draw upon the Higher Power, which I believe is available to me.

*Source: The American Journal of Alzheimer's Care and Related Disorders & Research, Nov/Dec 1989*