

Stages of Alzheimer's Care



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Stages of Care

Just as there are stages of Alzheimer's disease, there are stages of care as the disease progresses.

The Early Stage of Alzheimer's

Once the diagnosis is made, a number of important issues need to be addressed:

- **Learn all you can about the disease and the treatment options.** Contact The Alzheimer's Association to receive up-to-date information and to learn about workshops you can attend. Ask to be put on the mailing list.
- **Be confident about asking for a second opinion or choosing a new doctor.** You will need to be an advocate for your family member.
- **Get legal and financial affairs in order.** This is the time to execute a durable power of attorney for finances and health care and a living will, or to update these documents. Later in the disease process, the person with dementia will not be able to make these kinds of complex decisions. Without a durable power of attorney in place, a guardianship may be needed to make medical and placement decisions.
- **Driving will become a dangerous activity in the near future.** Enlist the help of your doctor if necessary to suspend driving privileges before an accident occurs.
- **Attend a support group.** It will give you an opportunity to share information, give and receive mutual support and encourage coping skills.
- **Monitor your family member closely** to make sure that medicine is being taken properly, personal hygiene is adequate, balanced meals are being eaten, and wandering is not occurring. Be prepared to provide assistance as needed.

The Middle Stage: Staying a Step Ahead

The middle stage of Alzheimer's disease is the longest, lasting 2 to 10 years, and is characterized by worsening mental function, increased confusion, and often-disruptive behaviors. The person in this stage cannot live alone and the caregiver(s) must assume more responsibility for their financial and physical well-being. A person in the middle stage of Alzheimer's disease requires full-time supervision.

- **During this phase, the person with dementia may start to have delusions (false beliefs) and hallucinations (seeing and hearing things that are not there).** Understandably, this can be very frightening to them, and they may respond by being very argumentative and accusatory, acting out, or even striking out! The disease is making it increasingly difficult for them to control their impulses.
- **Also, in the middle stage, persons with dementia commonly resist bathing and other aspects of personal grooming.** They may have trouble finding their way to the bathroom, or knowing what to do once they get there. Toileting accidents may occur.
- **Social isolation becomes a real concern for both the caregiver and the person with Alzheimer's disease.** The "odd" appearance of the person with dementia becomes noticeable to most people, and may make being with others who do not understand the disease very uncomfortable.
- **Persons with dementia may experience tremendous swings in their appetite.** The caregiver will need to be more diligent to ensure proper nutrition, particularly if the person has other medical conditions.
- **Sleeping problems are common in the middle stage.** The person with dementia may sleep at odd times of the day and often disrupts the household at night. They are frequently restless and do repetitive things such as pacing the floor or rummaging through drawers and closets.
- **Problems with balance and an unsteady gait become a concern.** At the same time, because of a loss in their physical coordination from the disease, persons with dementia may have difficulty with balance and are at risk for falls.
- **Wandering becomes a concern.** They may not recognize familiar surroundings and preventive measures to prohibit wandering and getting lost need to be in place.

- **A simple and supportive daily routine is helpful.** Persons in the middle stage need a simple and supportive daily routine that provides them with exercise and meaningful activities.
- **Effective communication skills make a difference.** It is suggested that everyone interacting with your family member with dementia learn how to communicate with them effectively. As the disease progresses, persons with dementia lose the ability to organize their thoughts, or to remember the meaning or usage of words. Using some simple techniques to communicate with them can reduce anxiety, improve self-esteem, and decrease problematic behavior.
- **To better cope with the difficult behaviors that characterize this phase,** it is important for caregivers to remember that the person's behavior may be "normal" for the disease. We need to remind ourselves that the person's brain is being affected with a horrible affliction, and that the behavior is not directed at us.
- **It is helpful to reminisce and remember the good times.** Looking at a memory book, old photos or videos may help to care for the person who is increasingly difficult to love.

During the Middle Stage Respite, Support & Knowledge are Important!

The middle stage, often referred to as the confusion phase, becomes obvious when the person can no longer hide the illness from others. At this stage, the person with Alzheimer's disease becomes easily confused and cannot be safely left alone. As the caregiver of a person in the middle stage, you will need ongoing help and support. Consider using the following resources:

Support Groups

Support Groups help by giving you a chance to meet others who are facing similar challenges and issues. Ideas are exchanged, problems are discussed, and solutions are explored. It will not take long to become comfortable sharing your problems with such a group.

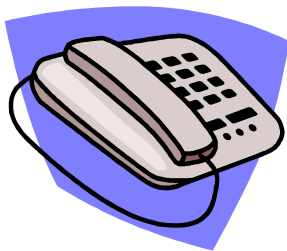
Respite Services

It is wise to consider some respite services. You may choose an Adult Day Care facility or have someone come into your home to relieve you for a few hours on a regular basis. Some nursing homes and assisted living facilities offer monthly, weekly, or weekend respite care. These options are especially helpful if you become ill, if you need to take a short trip, or if you need a longer break.

IT IS IMPERATIVE FOR YOU TO RECOGNIZE THAT YOU CANNOT DO THE JOB OF CAREGIVING ALL ALONE WITHOUT RELIEF!

Future Planning

The middle stage is a time when you may want to start thinking about future housing options, even if you feel you may never move your family member to a nursing home. Many people try to keep the person with Alzheimer's at home as long as they can, but in some cases the care demands may become impossible to meet at home. It is helpful to begin planning before a crisis occurs. This will allow you time to visit a number of facilities and to decide what will best meet your needs as opposed to making a hurried decision while under pressure and stress.



On-going Support through the Alzheimer's HELPLINE

The Western & Central Washington State Chapter of the Alzheimer's Association is here to help you learn to cope with the increased confusion, difficult behaviors and decisions facing you during this stage. We understand what you are experiencing and urge you to call us as problems present themselves. We have a variety of brochures,

books, videos, and other resources that you may find very helpful. For more information about these informational materials, contact our **HELPLINE** at **206-363-5500** or **1-800-848-7097** between 8:30 AM and 5:00 PM, Monday through Friday.

Late Stage Dementia

- **In the late stage of Alzheimer's disease, the brain is no longer able to tell the body what to do.** The person cannot walk or eat without assistance, and becomes incontinent of bowel and bladder. There is severe cognitive decline and all verbal abilities are lost. There is little purposeful activity. Loved ones are no longer recognized. Since at this time patients are immobile, they are at great risk for skin breakdown, contractures, elimination problems, pneumonia, and other infections. As Alzheimer's disease usually advances quite slowly, the patient might be 10 or even 15 years into the disease process before they reach this stage.
- **At this time, families are also at risk because of emotional overload.** Families may be caring for a person who can no longer respond (even those feisty comments are missed at this stage) and may not want to visit a person in a fetal position, whose hands and arms might be contracted. The time is approaching to let go of this person who has been slowly dying and whose unique personality has been changing.
- **It becomes necessary for family discussions about medical issues.** If the person with Alzheimer's does not have a living will, the family must agree on what comfort measures or medical procedures this person would have wanted.
- **The late stage is a sad time but also a time to prepare for a comfortable and dignified death.** Nursing home placement is very common at this time. If home care is the choice of the caregiver, daily help is needed and hospice care can be explored.
- **Hospice is a program of nursing care that is covered under Medicare and provides comfort measures only for those in the end stage of any terminal illness, including Alzheimer's disease.** Not only do nurses provide care but also they talk and counsel with the family. The family counseling continues for one year after the death of the patient. The patient is never transferred to a hospital for aggressive treatment but is allowed to die either at home or in the nursing facility.

- **There are important medical decisions to be made by the family at this time.** When death is inevitable, many choose to provide comfort measures only, such as pain medications and oxygen. This includes choosing to forego antibiotics to treat infections since they will only prolong the dying process and will not cure the underlying problem – Alzheimer’s disease.
- **Eventually the swallow reflex no longer operates and the person with Alzheimer’s disease cannot swallow food or water without choking.** The issue of placing a feeding tube in the stomach becomes a real point of discussion. If there is no artificial feeding, the person will die of dehydration. “Research and clinical evidence reveals that death by dehydration is a very compassionate and comfortable way to die. On the other hand, hydrating by a feeding tube or IV prolongs the dying process and may make it more uncomfortable by filling the body with fluids which can gather in the throat and lungs.” (1998 Dunn, H., *Hard Choices for Loving People*, A&A Publishers, Inc.).

This is a very emotional time for families. It is strongly recommended that families read materials and discuss planning options long before major decisions need to be made. Attending support group meetings can be extremely beneficial at this time. Only those facing these same decisions can understand the agony of making such difficult choices. Letting go is always difficult, even when someone has been ill for a long time.