

## **ALZHEIMER'S: WHAT TO EXPECT AS THE DISEASE PROGRESSES**

The course of Alzheimer's disease can vary significantly with each individual. However, some changes are more typical and so you can reasonably expect to experience them. For example, the behavioral changes that usually dominate Stage I are joined with overriding physical problems in Stage III. Educating yourself to the flow of Alzheimer's can help you communicate better with your parent, your family and friends, and your parent's physician.

AD systematically destroys your parent's ability to use and rely on the critical skills and cognitive functions we develop from infancy through adulthood and take for granted, such as memory, orientation to time and place, judgment that allows us to discern right from wrong or safe from harmful, and problem solving. Your parent will lose the instincts and memories that are needed to function safely and appropriately in all areas of living: driving, self-medicating, eating, writing, reading, cooking, interacting socially, cleaning, playing sports, grooming, and making financial or legal transactions. The list is endless. The loss is all encompassing.

### **What to Expect in the Three Stages of Alzheimer's Disease**

Use the box to the left of each symptom to check those that apply to your parent. Check all that apply, even if you cross over to another stage. Feel free to check off symptoms in more than one Stage. This information can help you create plans to keep your own mental, physical, and financial future intact. Taking this list to your parent's physician will provide her with an insider's clear written account of your parent's behavior and abilities. The physician will be more able to prescribe appropriate lifestyle and medication changes that may help improve the entire family's quality of life.

## **Changes Commonly Experienced in Stage 1**

In the early stages of AD, you can expect your parent to show consistent, increasing memory loss, especially about recent events. You'll notice minor difficulties in handling everyday matters, less interest in hobbies, some disorientation to time and place, and perhaps a need for prompting to keep appointments or continue an established personal care or household routine. If your parent plays card games needing strong memory skills for counting cards and suits, that may become progressively more difficult. Because safe driving entails remembering how to start, brake, steer, reverse, park, read road signs, obey speed limits, and use landmarks and clues to get from one point to another, driving for a parent with AD is always considered extremely dangerous for him and for all others on the roads and streets.

Although Stage 1 is called the 'mild' stage, it is actually one of the most difficult periods of the disease process for you and your parent. Most people in Stage I AD realize that they are losing control and fight back by denying the existence of the problem. Their children also find it easier to deny the disease and attribute problems to "getting older." These combined denials mean delayed diagnosis and treatment, often putting the person with AD at more risk. An early diagnosis by a board certified neurologist specializing in AD can result in Mom's receiving medications that may help slow the progression of the disease. Treatment at an early stage gives Mom the potential to retain a higher functioning level for a longer period of time.

### **Short Term Memory Loss, Confusion, Focus**

/\_/ My parent is beginning to forget recent experiences such as appointments made yesterday or last week.

/\_/ She has trouble with new experiences such as a new telephone number or area code, or meeting someone new.

/\_/ My parent sometimes has trouble finding familiar places like her home or mine, the grocery store, and the doctor's office.

### **Speech/Conversation**

/\_/ My parent has had word finding problems and has filled in the sentence with a non-related word or made-up words that sound like gibberish to cover the difficulty.

/\_/ My parent seems to be talking less. (This may help avoid having to find words or making another embarrassing mistake.)

### **Initiative/Self Care**

/\_/ My parent has difficulties with decisions on menus or selecting clothing to wear.

/\_/ My parent has begun to make inappropriate driving decisions.

/\_/ My parent has begun to make inappropriate financial decisions.

/\_/ My parent has lost interest in hobbies, friends, and other activities.

/\_/ My parent is not as well groomed as she used to be.

/\_/ My parent doesn't appear to bathe as often as she used to.

### **Personality/Mood Changes**

/\_/ My parent has mood swings that he didn't have before AD.

/\_/ My parent makes excuses to avoid friends and family.

/\_/ My parent has become depressed.

/\_/ My parent has experienced a reversal in personalities from kind to nasty, outgoing to reclusive, gentle to sharp tongued, or other obvious and significant changes.

In the moderate stages of AD, you'll notice significant memory loss. The AD patient will have retained fewer and fewer memories, will be more severely disorientated about time and place, will have great difficulty in problem solving, and will be unable to handle social relationships or function independently except for simple tasks. Your parent will need an increasing level of assistance with dressing, grooming, preparing meals, taking medications, handling

most household activities, driving, or making sound decisions regarding personal safety and finance.

### **Changes Commonly Experienced in Stage II**

Memory and cognitive ability continue to deteriorate in Stage II, which make supervision and assistance a primary need. Preparations for this stage include considerations for 24-hour assistance, transportation, housing, financial and legal matters, and long-term care.

Medical assistance and caregiver respite are mandatory for your parent's safety and yours, and to control your quality of life.

#### **Increased Confusion:**

/\_/ My parent has difficulty remembering to lock the door.

/\_/ My parent cannot remember how to call me if she needs help.

/\_/ My parent cannot formulate complete thoughts and sentences.

/\_/ My parent cannot read.

/\_/ My parent may mix up identities or forget names and identities (daughter, son, grandchild, friends, and deceased relatives).

/\_/ My parent doesn't recognize or remember the use of objects like a chair or bed.

/\_/ My parent shows frustration at not being able to understand or at not being understood.

**Speech/Actions**

/\_/ My parent repeats questions or statements many times.

/\_/ My parent makes repetitive motions.

/\_/ My parent paces in circles or wanders from room to room.

/\_/ My parent often becomes unmanageable in the afternoons or evenings with verbal outbursts or physical activities such as masturbating or disrobing in public or running away.

/\_/ My parent makes up stories to fill in memory gaps.

**Hygiene Changes**

/\_/ My parent refuses to bathe or becomes fearful and agitated when we bathe her.

/\_/ My parent wants to wear the same pieces of clothing for extended periods of time without washing them.

/\_/ My parent is incontinent.

**Sleep/Paranoia/Fear**

/\_/ My parent sometimes or always sleeps during the day and stays awake at night.

/\_/ My parent has accused us of trying to kill her or stealing her money.

/\_/ My parent is sometimes aggressive or combative and has tried to kick, hit, scratch, or bite other people.

## **Safety Risks**

/\_/ My parent lives alone and gets lost when he goes outside his home.

/\_/ My parent no longer understands what poison is or does.

/\_/ My parent is unsure of himself on stairs or balconies.

/\_/ My parent's balance is off and he is at risk for a trip or fall.

/\_/ My parent can no longer dial my number on the phone. (Try this test: hand your parent the telephone and say, "Dial my number, Mom.")

/\_/ My parent could no longer evacuate in a fire.

/\_/ My parent could no longer remember how to call 911 in an emergency.

At the more severe levels of impairment, your parent may not remember you, your siblings, or a spouse. It will no longer be safe to leave your parent alone. Your parent will require twenty-four-hour supervision and total assistance with all activities of daily living such as eating, bathing, dressing, and toileting.

*"Mom is only sixty-eight years old, but she is at the end stage of AD. I want to spend as much time with her as I can, but it's very hard to see her this way. Sometimes she cries for the baby son she lost forty years ago. A nurse who visits Mom once a week suggested we give her a baby doll to hold. Her home health aide said that when Mom becomes upset or agitated, she gives her the doll and Mom rocks it to sleep in her arms. Sometimes I wish I was the baby doll."*

Fran, Minnesota

### **Changes Commonly Experienced in Stage III**

Stage III is also known as “end-stage” Alzheimer’s, because it signifies the final years of the disease. At the end of this stage, your parent will pass away. Assistance from a counselor at your local Alzheimer’s organization and hospice, and a physician specializing in Alzheimer’s disease and related dementias can help you and your parent enormously during this very difficult time.

#### **Assistance**

/\_/ My parent needs total assistance with transferring from bed to chair, eating, walking, and every activity of daily living.

/\_/ My parent has difficulty swallowing.

/\_/ My parent refuses to eat.

#### **Memory**

/\_/ My parent no longer recognizes himself or family members.

#### **Speech**

/\_/ My parent rarely or never communicates.

#### **Body and Functions**

/\_/ My parent sleeps most of the time.

/\_/ My parent has had a significant weight loss.

/\_/ My parent’s skin bruises or tears easily

/\_/ My parent is completely incontinent of bowel and bladder.

One of the results of society's continuously expanding Alzheimer's knowledge is that AD is a long-term disease. Patients may survive as long as twenty years from diagnosis to death—meaning you may find yourself in the position of caregiver for two years or two decades. Caring for a loved one with dementia is considered one of the most difficult jobs in the caregiving spectrum. The financial losses, loss of quality of life, and loss of *self* make it vital to get help.

Ongoing support and caregiver education can help avoid or minimize the effects of depression and loss of quality of life by supplying you with the information you need to understand the illness and make informed decisions.

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