

## Stages of Alzheimer-type dementias

**Purpose: To introduce patients and families to seven roughly defined stages of Alzheimer's and assess the stage of disease based on typical functional losses**

### How long will the dementing illness last?

The length of a dementing illness depends on several things:

- The type of dementia –Some dementing illnesses such as Creutzfeldt-Jakob disease progress rapidly while others, including Alzheimer's disease, may last 20 years or longer.
- The age of the person with dementia - As a general rule, the younger the person with the disease, the more rapid the progression, although this is not always true. Plus, someone who develops a dementing illness at age 85 or 90 does not generally have a 20 year life expectancy.
- The number and severity of other physical conditions and limitations – A 65 year old person with dementia might live longer than a 65 year old person with dementia, diabetes, hypertension, and heart disease
- The degree of mobility and engagement of the person with dementia - People who have led sedentary lifestyles (“couch potatoes”) tend to develop more problems with mobility, which leads to falls and a shorter disease course than people with dementia who remain active.

### Staging dementia

Research on the length and stages of dementia has been done primarily for people with “Alzheimer-type” dementias as they are the most common. Thus, the stages listed below are most valid for people with Alzheimer's disease. If your family member or friend with dementia has been diagnosed with a different dementia such as frontotemporal dementia or Lewy body dementia, consult with your physician or provider about staging the illness.

Most dementing illnesses average 7-15 years in length, but it is not uncommon for people to live as long as 20 years with the illness. Families always want to know what stage of the illness their loved one is in, what comes next, and how long the person will live. While no one can answer the last question, the first two are a bit easier.

Most experts agree there are roughly seven stages of dementing illnesses. While we can try to estimate stages using tests, such as counting backwards by 7's or 5's, it is actually more helpful to look at the person's usual day to day function to do so.

When comparing the stages below the person with dementia's abilities, select the stage with the highest number where you see functional changes. For example, if the person is unable to bathe without direction and has no losses beyond this, we place the person in stage 5. Because the disease is progressive, the person will also have many of the symptoms listed in stages 2, 3, and 4.

The seven approximate stages are as follows:

- 1. No cognitive decline - Mild Cognitive Impairment**
- 2. Very mild cognitive decline – Forgetful stage**
- 3. Mild cognitive decline - Early confusional**
- 4. Moderate cognitive decline - Late confusional**
- 5. Moderately severe cognitive decline - Early dementia**
- 6. Severe cognitive decline - Middle dementia**
- 7. Very severe cognitive decline - Late dementia**

**Changes in functional abilities by stage - While no one has all of the losses in each stage, the following can help you to determine your loved one's progression through the illness.**

**1. No cognitive decline - Mild Cognitive Impairment**

People at this stage may complain of being forgetful or may have difficulty remembering names. At this point in the illness it is very difficult to diagnose whether or not this will progress to become a dementia, however, it is extremely important to seek medical attention at this time. Module 4 will help with understanding what needs to be done in stage 1.

**2. Very mild cognitive decline – Forgetful stage**

- The person will have changes in short-term memory or a decreased ability to learn and retain new information
- May have symptoms of depression or apathy, and also may refuse treatment for it
- The person may develop a “short fuse,” becoming angry more easily; and have new conflicts with others (especially marital conflict)
- The person may report increasing frustration, increased anger
- There may be an increase in intensity of emotions including sadness or happiness over seemingly minor things
- The person may seem willful, purposeful, or increasingly self-absorbed
- If still employed, the person may develop problems with employer or have poorer job performance

**3. Mild cognitive decline (Early confused stage)**

There will be actual changes in the person's ability to do the following without direction, supervision (oversight), or modifying the task, or the person may require actual help from another person:

- Manage employment
- Plan for investments, pay bills, balance the checkbook, and generally manage the more complicated financial responsibilities.
- The ability to drive begins to change. The person may miss intersections, have trouble following signals or signs, drift across lanes, follow more closely or too far away, drive slower or too fast, ask directions in familiar places, make wrong turns, become angry with other drivers, have fender benders or mishaps, and/or generally begins to make mistakes.
- There may be a change in the ability to make decisions about purchases and shop. The person may have difficulty counting change and may simply hand their billfold to a clerk to take the amount needed for a purchase.
- There may be problems with accessing computer sites, such as not being able to find sites they have used before, or the person may begin to surf risqué sites.
- The person may be unable to attend to the details of planning vacations and trips.
- Have difficulty comprehending and remembering complex written materials.
- The person may begin to spend more than before – especially on credit card purchases, magazine subscriptions, telephone calls, or TV or mail order products, and may actually be vulnerable to financial exploitation from these solicitations.
- The person may become a victim of phone or internet scams.
- The person will have difficulty with dialing the phone in an emergency, and taking messages.

- May have difficulty with power implements (snow blowers, saws, gas tanks) and will become unsafe with firearms.
- Participation in social activities may change such as wanting to leave large social gatherings, not wanting to attend usual social activities.

#### **4. Moderate cognitive decline (Late confusional stage)**

- Decreased time sense characterized by obsessing over appointment times, getting dressed early for scheduled events, and worrying about when things will occur.
- The person has a general loss of reading comprehension and becomes unable to remember what they have read.
- The person's ability to remember what is said on the phone and dial the phone declines.
- The person's ability to determine clean versus dirty in the household may decline. They may not clean without being told or may begin to clean obsessively. Linens may go unchanged for long periods of time. Many people will stop using the washing machine and begin to wash clothing by hand. The bathroom may be soiled. The house may develop clutter as the person does not know what to throw out or may develop a dusty "no one lives here" look.
- Changes in cooking abilities take place in a variety of ways:
  - The person may use a single pan to cook all meals.
  - The person might only eat frozen prepared foods or foods that require no preparation such as sandwiches, crackers, or commercial supplement drinks.
  - The person may begin to eat all meals in restaurants.
  - There may be evidence of food that has been burned.
  - The person may begin to lose weight.
  - The family might find food stored inappropriately or find food rotting in the refrigerator.
  - Dishes pile up in the sink.
  - Food is plugging drains.
  - The stove has been left on.

- The thermostat settings are either too hot or too cold. If the thermostat is set too high, the person may have the windows open to compensate instead of turning down the heat. The person may wear an overcoat in the house.
- The person begins to withdraw from complex tasks such as participation in social or religious organizations or preparing for holidays. This can include service clubs, holding an office in an organization, or participation in a card club.
- There is usually a loss of the sense of “risk,” knowing that things are dangerous and/or having “close calls.”
- The person can exhibit increased irritability, frustration with activities, and self-absorption.
- The person may avoid making advanced directives and other complex activities due to difficulty with planning.
- The person may deny the memory problem and become irritated when family tries to discuss it.
- The person may be angry about lost activities, especially driving and may lose their sense of humor.

### **5. Moderately severe cognitive decline (Early dementia phase)**

This stage starts the losses in basic self care activities which health professionals call “ADL’s,” or activities of daily living. The pattern of loss tends to occur in a reasonably predictable sequence but can be made worse by illness, medications, fatigue, and other factors (see Module 5).

- Bathing – This starts with the person failing to bathe regularly or becoming resistant when bathing is suggested. The person may develop an actual fear of water or showering with water cascading on their head. Module 10 will discuss methods for encouraging bathing.
- Grooming – The person may not clean their teeth, comb their hair, shave, or apply makeup as carefully as in the past. In addition, it is uncommon for the person’s clothing to be soiled from spilled food.
- Selecting clothing – The person may wear the same clothing day after day, even becoming angry when change is suggested or the clothing is laundered. Some people with dementia change clothing frequently throughout the day or begin to select odd combinations of clothing.

- Dressing – The person may need actual direction in order to get clothing on in the correct manner.
- By the time dressing is affected, the person may begin to have difficulty with recognizing friends or family members. This is generally intermittent at first.
- Non-recognition of TV, mirrors, pictures, objects – The person may report extra people or animals in the house triggered by misinterpreting anything that might represent the images they report. This is due to visual-perceptual deficits. The person may complain that glasses need to be changed.
- Withdrawal from activities and people due to sensitivity to noise and too much visual stimulus.
- The person with dementia clings to his/her caregiver, fearful whenever the caregiver leaves, even for a short time.
- Repetitive behaviors – The person may ask the same question repeatedly, despite hearing the answer. The person may fixate on or endlessly repeat a particular activity.
- Decline in language ability – At this stage the person's ability to hold a conversation is notably poor. Often they do not understand everything that is said.
- There may be resistance to intimacy.
- The person develops a child-like emotions, almost as if the developmental steps of childhood are reversed. While the person does not become a child, their ability to reason, make decisions, and cope mirror those of various stages of childhood, including becoming increasingly self-centered.
- There is the beginning of regular behaviors that may include the following. Once identified, many of these behaviors can be managed successfully.
  - Pacing – walking back and forth without a real destination.
  - Wandering – walking without a purpose or goal.
  - Sleep disturbances – usually waking at night thinking it is morning or waking in the night confused.
  - Late day confusion or agitation.
  - Belligerence when asked to bathe
  - Demanding to leave social events early.
  - Agitation.
  - Aggression – usually related to resisting care.
  - Having illusions of children or adults in the house.
  - Not recognizing family or home when tired or stressed.

## 6. Severe cognitive decline (Advanced Dementia)

- Toileting
  - Initially the person may urinate or have a bowel movement in unusual places. This is often because the person does not recognize who is in the mirror and thinks someone else is in the bathroom and looks for another place to go.
  - Night-time urinary incontinence.
  - Inadequate cleansing after a bowel movement.
  - Eventual total loss of control over bladder and bowels.
  
- Ambulation (walking)
  - Shuffling.
  - Coasting from object to object.
  - Difficulty rising from chair.
  - Feet getting “glued” to the floor.
  - Falling – Falls while walking are likely As the person weakens, falling from bed is likely to happen because he/she does not know to call for help and gets up spontaneously whenever they feel the need. Bed or chair alarms only tell of an emergency and may make the person bolt. Side rails have been shown to cause worse injuries as most patients will climb over them. Using a belt or tie to keep the person in bed or a chair may result in strangulation, suffocation, acting out, or screaming and should be avoided at all costs.
  
- Toddler-like emotions.
  
- Changes in eating including the following:
  - Failing to eat unless served.
  - Eating with fingers.
  - Easily distracted when eating – may need multiple small meals.
  - May put non-food items in mouth.
  
- Regular non-recognition of family.
  
- Very poor language ability.

## 7. Very Severe cognitive decline (Late dementia to death)

- Loss of ability to move about purposefully, i.e. pushing a wheelchair.
- Loss of regular verbal communication.
- Dependence in all activities of daily living.
- Needs to be fed:
  - May choke on thin liquids such as water, tea, coffee.
  - May choke on meat.
- Loss of recognition of family members except during moments of clarity.
- Spontaneous behaviors, such as yelling, tapping or banging.
- Contractures – where the joints are “frozen” in a flexed position.
- Pathologic (spontaneous) fractures.
- Severe weight loss.
- There is a strong potential for skin breakdown and/or skin tears.
- Repeated infections – especially pneumonia and urinary tract infections.
- Aspiration – breathing in food, fluid, or saliva, causing pneumonia.
- Falls from bed (rollouts or climb-outs).
- Return of primitive reflexes – These are the reflexes seen in infancy that disappear after the first 3 months of life.
- Seizures, additional neurological problems.

Unfortunately these stages are not as distinct as outlined here. Most health providers use an average of what the person can do over a period of a week or so. Patients may improve slightly with medications or worsen temporarily due to fatigue, the wrong environment, or when there is too much change.

## NOTES:

### Key Points to Understanding the Approximate Stage of Alzheimer-type Dementias

1. Life spans of people with a dementia differ enormously because of the varying ages of people at the onset of the disease, the number and type of other illnesses they have, the degree to which they remain active and involved, and the type of dementing illness.
2. Research has identified roughly 7 stages of Alzheimer's disease, although it is not uncommon for people with dementia to follow a different pattern.
3. A family may estimate the stage of the person's illness by comparing the person's average day to day function with the stages described in this module.
4. It is important to remember that illness, pain, medication reactions, fatigue, changes in location, and other factors may make the person with dementia's function appear worse.