

For the Person Completing the Dartmouth Dementia Directive: Understanding the Different Stages of Dementia

Note: This document should be used by the person completing the Dartmouth Dementia Directive (the "principal") as a guide to understanding the typical features, abilities and disabilities of the different stages of dementia. For agents and medical providers who need to determine the stage of dementia of a principal who has developed dementia, please see the document, "Determining the Stage of Dementia (for Agents and Medical Providers)," below.

In most individuals with dementia, the condition progresses gradually from mild to severe usually over a number of years. This pattern of progression is certainly the case with Alzheimer's disease, the most common form of dementia, but it is generally true in most other dementias as well.

There are a number of different staging systems which are used in dementia, but the most common, and most reliable, is to simply describe the illness as "mild," "moderate" or "severe". While staging can be helpful in a number of different ways, it is important to realize that no person fits perfectly into any one stage, and that, at times, individuals can seem to fluctuate between one stage and another. For example, someone who generally meets criteria for the *moderate* stage of dementia, may, on a "good day", appear to have many features characteristic of *mild* dementia. However, if fatigued, acutely medically ill, or under other stressful circumstances, that same individual may show features of *severe* dementia. The overall, baseline level of severity should be used to determine the stage of dementia.

The following descriptions apply to people with dementia in general, although not all characteristics are listed here, and some individuals may be harder to classify than others. Following a general description of the stage, specific features are given using the general categories which are assessed by the Dementia Severity Rating Scale (see below).

I. Mild Dementia:

It can be difficult to determine when someone with cognitive problems worsens to the point where he or she can now be said to have dementia, and so far, there are no objective, scientific methods to establish this. In general, someone is diagnosed with dementia when he or she is no longer able to do one or more so-called "instrumental activities of daily living" (IADLs) independently. IADLs include shopping, cooking, handling finances, driving, managing one's medications, and the like. An indicator of an impairment in IADLs would be someone who had been able to cook who now needs assistance with following a recipe or knowing the proper sequence of steps in preparing something in the kitchen. Another indicator may occur in someone who had been able to handle their own finances – paying bills, writing checks, calculating restaurant tips, etc. – but now needs to have someone help with one or more of these tasks. A third example might be someone who was able to drive to the store and do the grocery shopping without omitting important items or buying unnecessary things who now has trouble driving there, perhaps getting lost on the way, running through red lights or stop signs, or scraping other cars in the parking lot. Once in the grocery store, he or she may not be able to make all of the correct purchases, even with a written list. Along with impairment in one (or more) instrumental activities of daily living, a number of other signs and symptoms of dementia are usually present as well.

Although there are definite signs and symptoms of illness in mild dementia, most individuals are able to live at home and may even live alone but generally need someone to assist them regularly with various tasks.

While the rate of progression of dementia is quite variable, a person with Alzheimer's disease may remain in the mild stage for up to two years and sometimes longer. Medication treatment may prolong this in some

cases. In other forms of dementia, the duration of the mild stage can be quite variable.

Specific Areas Affected in Mild Dementia:

Orientation: People with mild dementia may be disoriented to time, meaning that they are unaware of the general time of day, the date, day of the week, month, season or year. Many people, particularly those who do not go to work every day, have trouble keeping track of the day of the week, or the precise day of the month, but someone with mild dementia may be *considerably* incorrect about this; he or she may state that it is Friday when it is really Monday, or that it is the 10th when it is actually the 29th of the month. People with even mild dementia may be incorrect about the year, not just in January (when many people mistakenly say or write the previous year) but at other times as well. They may miscalculate by more than one or two years.

Persons with mild dementia may become confused about location when they are in a new place, but generally recognize whether or not they are at home. They will usually be able to correctly state their home address, town or city, but they might mistakenly give an address at which they lived at some point in the past.

Memory: Nearly all forms of dementia cause impairment in *recent* memory: those events which have occurred minutes to weeks earlier. Some degree of impairment in recent memory is nearly always present in mild dementia. *Remote* memory (memory from years ago) is generally not impaired in mild dementia.

Speech and Language: People with mild dementia may show some difficulty with finding words, particularly proper nouns, such as the names of people and places. Naming difficulty can occur simply as a result of aging, but in mild dementia it is usually (but not always) more severe than in normal aging. Individuals with normal aging memory, but without dementia, are likely to eventually recall a name if they focus on it for a period of time, but recall is less likely to be successful in someone with mild dementia. Generally, people with mild dementia are able to comprehend what is said to them, unless it is said in a very rapid or confused manner. Of course, what has been said may be heard and comprehended but forgotten soon thereafter.

Recognition of Others: Generally, people with mild dementia are able to recognize family members and friends, particularly if they are seen with some frequency. Relatives or others who are seen infrequently may not be recognized, or it may take some time for the person with mild dementia to identify who they are. It is also possible that the nature of a relationship may be confused; for example, the person with mild dementia may mistake an adult child for a sister or brother, or someone related through marriage may be misidentified as a cousin or simply a friend.

Home and Community Activities: Individuals with mild dementia may appear to function normally at home, but, as noted above, instrumental activities of daily living (cooking, shopping, finances, driving, etc.) may be impaired and/or require the support and assistance of someone to successfully complete the task. On casual interaction with others, the person with mild dementia may not seem to have impairments. A more extended conversation, however, will often reveal forgetfulness or other abnormalities of thought.

Personal Care and Cleanliness: This can be variable. Some individuals with mild dementia will remain quite fastidious and appear normal to others. Others may appear less neat than they presented previously. They may wear mismatched clothing or items that are somewhat inappropriate for the season or the occasion. Standards of grooming and hygiene may be lower than they were previously.

Eating: Generally, people with mild dementia are able to eat independently. Table manners may be less good than had previously been the case. Occasionally, the wrong utensil, or no utensil, may be used to eat a food item – for example, eating vegetables with a spoon rather than a fork; or using one's hands to eat something that is normally eaten with a knife and/or fork, such as a slice of meat or a piece of cake or pie.

Continence: Individuals with mild dementia generally have no problem with bowel continence. There may be very occasional urinary incontinence, particularly if access to a bathroom is not readily available (while

traveling, for example).

Mobility and Traveling: People with mild dementia generally have no difficulty with ambulation (walking). They generally have no difficulty finding their way around their own house, unless they have just moved into a new home, in which case it may take some time to become familiar with the location of different rooms. Outside, however, they may become lost if they walk in less familiar territory or take a different route from one place to another. They may have difficulty with driving (getting lost, erratic driving or minor accidents) or may have given up driving completely. They may be able to take public transportation if the route is extremely familiar but can become lost or confused if using public transportation on a less familiar route.

Ability to Make Decisions: Individuals with mild dementia are usually able to make their own decisions, unless the choices presented are complex or abstract. They may become confused in complicated situations, or when plans are changed. Whether or not a person with mild dementia is able to make decisions regarding their own healthcare is variable and needs to be assessed carefully by the person's clinician.

II. Moderate Dementia:

Typically, the transition from mild to moderate dementia is a gradual one. As is the case with the transition from no dementia to mild dementia, there is no firm dividing line between mild and moderate dementia. Although someone with mild dementia, particularly in the earliest stages, may appear normal to the casual observer, the ability to maintain a normal social façade is usually lost by the time someone has progressed to moderate dementia. He or she is likely to appear impaired to even the casual observer. Mood and behavioral symptoms of various kinds tend to be relatively common in moderate dementia, although these can occur in mild dementia as well. Mood and behavioral symptoms include depression, anxiety, restlessness, irritability, agitation, paranoia, wandering and others. While no person has all of these symptoms at one time, and some individuals show little in the way of behavioral disturbance, most people with dementia have neuropsychiatric symptoms as part of the illness, and these are most prevalent during the moderate stage of the illness.

Persons with moderate dementia may live at home with considerable help from a care partner and others. Generally, they cannot be safely left alone for prolonged periods of time. People with moderate dementia may also live in a care facility, such as assisted living or a memory care center, in order to obtain the assistance and supervision they need on a daily basis. People are more likely to live in a care facility if there are significant behavioral symptoms or if there is limited family support available.

Moderate dementia may last for many years, and early moderate dementia may appear quite different than late moderate dementia.

Specific Areas Affected in Moderate Dementia:

Orientation: People with moderate dementia may not be aware of the day, date, month, season or year, although in early moderate dementia, some of these may be preserved. When at home, the person will usually be aware of his or her location, but at other times will not recognize that he or she is at home. Persons with moderate dementia are rarely able to maintain a correct awareness of where they are when they are not at home, unless it is a very familiar location (for example, church, or a diner or coffee shop visited often, etc.).

Memory: Short term memory is significantly impaired, and the person with moderate dementia will often rapidly forget what has just been said to them, or something which has very recently occurred. They may have difficulty remembering basic facts such as when they ate their last meal. Remote memories are generally better preserved, but these may begin to decline at this stage as well. People may have difficulty identifying

how many children they have, where they were married, or where they previously worked.

Speech and Language: The individual with moderate dementia is generally able to answer questions, but speech is often very difficult to follow and may be incomprehensible at times. The person may have difficulty getting his or her ideas across, although a care partner who knows the person well can often interpret what he or she is trying to say. The ability to understand communications from others is variably affected; the person with moderate dementia generally cannot process more than one simple idea at a time and may not be able to follow simple instructions, either because the instruction is not understood or because it is rapidly forgotten.

Recognition of Others: The person with moderate dementia may have difficulty recognizing even close family members, and by late moderate dementia may no longer appear to recognize the spouse. Other individuals less close are frequently not recognized.

Home and Community Activities: The person with moderate dementia often has difficulty interacting with people outside the home and will need considerable help and support from the care partner in social settings. He or she may be able to participate in simple home activities with family or close friends. The person with moderate dementia usually appears impaired even to the casual, untrained observer. The individual generally needs considerable assistance with or is completely incapable of performing any instrumental activities of daily living. He or she may passively look at television but is generally unable to follow the plots of shows or understand what is happening on the news. If he or she is still reading, there is limited understanding of what is being read, and it is likely that reading will be discontinued by late moderate dementia. If the person with early moderate dementia is still driving, this needs to stop at this point for the safety of the individual and others.

Personal Care and Cleanliness: The person with moderate dementia may perform his or her own hygiene, but often needs assistance with this, such as reminders to wash or bathe. Generally, assistance is needed with selecting clothing and sometimes with putting items of clothing on in the proper sequence. The person may need to be reminded to properly clean after toileting.

Eating: Generally, people with moderate dementia are able to feed themselves but may need some assistance with cutting meat or other eating activities. They can become easily distracted during meals and may need reminders to continue to eat. Table manners are often quite poor.

Continence: More frequent episodes of urinary incontinence occur at this point and the individual with moderate dementia may need reminders to go to the bathroom regularly during the day, particularly before leaving the house. Bowel incontinence may occur occasionally during the moderate stage of dementia, although that is not always the case.

Mobility and Traveling: The ability to move around the home independently is usually preserved, although the person may have trouble finding certain rooms, such as the bathroom. Outside, individuals with moderate dementia need to be closely monitored as they may wander away and become lost. Usually, they cannot travel alone safely on public transportation. As noted above, the person with moderate dementia should not drive as a matter of safety for self and others.

Ability to Make Decisions: The person may be able to make very simple decisions if given concrete choices (e.g., expressing a preference for a sandwich or soup for lunch) but often has difficulty making consistent decisions of greater complexity. This is generally due to the fact that the issues needing to be decided are not well understood or are quickly forgotten, and the ability to clearly express a preference is impaired or absent.

III. Severe Dementia:

Persons with severe dementia are generally out of contact with their environment, family, and others. They tend to be generally inattentive to all that goes on around them in the present. People with severe dementia need continuous care from others for survival. It may be difficult to provide that level of care and assistance at home, and many persons with severe dementia live in an institutional setting, such as a nursing home or perhaps an assisted living dementia care unit.

Severe dementia can last for several years. Longevity will depend on the overall state of physical health of the person, the quality and attentiveness of care they receive, as well as other factors. People with severe dementia will either die from complications of the disease (such as pneumonia, complications from a fall, etc.) or an unrelated illness, such as a stroke or heart attack. It is impossible to predict with any accuracy when death will occur.

Specific Areas Affected in Severe Dementia:

Orientation: To the extent it is possible to determine orientation, people with severe dementia are nearly always disoriented to time, in every aspect, as well as to place. When at home they do not appear to recognize the environment as such, although moving to a different environment can be disruptive if the interpersonal attention received in the new environment is significantly different than previously.

Memory: People with severe dementia have very poor or non-existent recent memory. New information, if retained at all, is generally retained for brief moments, only. Longer-term memories are severely impaired as well or are not accessible due to retrieval and/or communication deficits. People with severe dementia may be able to state their own name, but this is sometimes forgotten, as are other very basic facts of their personal biography.

Speech and Language: Speech is generally absent or limited to a few words. Communications, to the extent they exist, are usually not intelligible. The ability to understand what is said by others is extremely impaired, as well.

Recognition of Others: People with severe dementia generally show no recognition of those who attempt to interact with them. They may not recognize even close family members, including the spouse, children, or other close relatives or friends.

Home and Community Activities: The individual with severe dementia does not participate actively in any activities at home or elsewhere. However, there may occasionally appear to be some degree of enjoyment or calming associated with listening to music, with food or drink, or with stimulation of other sensory modalities

Personal Care and Cleanliness: The person with severe dementia is completely dependent on others to provide personal care related to hygiene, dressing, and all other aspects of personal care.

Eating: Individuals with severe dementia are unable to feed themselves and need to be fed by others. They may display some pleasure associated with certain foods or beverages and will usually be able to indicate when they are satiated.

Continence: Bladder continence is usually completely lost, and the person may be incontinent of bowel as well. He or she needs complete assistance with cleaning him or herself after a bowel movement.

Mobility and Traveling: People with severe dementia are unable to travel independently and may show agitation when taken from one setting to another. They usually do not know their way around the house, if they retain any ambulatory ability. Eventually, all ambulation is lost, and the person is generally confined to bed or an easy chair.

Ability to Make Decisions: No ability whatsoever to make decisions regarding care remains. The person may demonstrate a preference between two simple choices (e.g., between two items of food) but this may be inconsistent and unreliable.