

Towards an Understanding of Living and Dying with Dementia¹

Dementias are life-limiting illnesses that affect a person's memory, thinking, behaviour, and ability to perform everyday activities (World Health Organization, 2019). There are many types of dementias, with Alzheimer's dementia being the most prevalent.

Dying with dementia has been called "death by a thousand cuts," drawing attention to the multiple losses experienced by the dying person and the family. Dementia worsens over time as brain cells die. A person with dementia will lose the ability to think, speak, solve problems, and evaluate risk, as well as experience changes in moods and behaviour. Eventually, the person will lose the capacity to perform personal care and more basic functions, such as the ability to talk, eat, and swallow.

While people with Alzheimer's dementia lose the ability to care for themselves long before they are imminently dying, people with other types of dementia, for example, vascular dementia, may die following one or a series of strokes.

The challenges of supporting a person with dementia include the uncertainties of the decline and experiencing multiple losses and ambiguous losses. What is certain with dementia is that a person will progress to a stage with fewer and fewer abilities.

The **Global Deterioration Scale of Dementia**² (shown below) is a tool that can help families understand the process of decline in Alzheimer's disease. Family can read for the signs and symptoms their loved one is experiencing and learn about the current stage. They can see the average duration of the current stage, which is especially helpful when planning for the person's care needs.

Although the scale shows discrete stages in deterioration, it is important to note that a person often has characteristics of more than one stage, and may not have all characteristics of each stage. People with other chronic illnesses will decline at different rates.

Global Deterioration Scale / Reisberg Scale			
Diagnosis	Stage	Signs and Symptoms	Expected Duration of Stage
No Dementia	Stage 1: No Cognitive Decline	In this stage, the person functions normally, has no memory loss, and is mentally healthy. People with NO dementia would be considered to be in Stage 1.	N/A
No Dementia	Stage 2: Very Mild Cognitive Decline	This stage is used to describe normal forgetfulness associated with aging. For example, forgetting names and where familiar objects were left. Symptoms of dementia are not evident to the individual's loved ones or their physician.	Unknown
No Dementia	Stage 3: Mild Cognitive Decline	This stage includes increased forgetfulness, slight difficulty concentrating, and decreased work performance. People may get lost more frequently or have difficulty finding the right words. At this stage, a person's loved ones will begin to notice a cognitive decline.	Average duration of this stage is between 2 years and 7 years.
Early-stage	Stage 4: Moderate Cognitive Decline	This stage includes difficulty concentrating, decreased memory of recent events, and difficulties managing finances or traveling alone to new locations. People have trouble completing complex tasks efficiently or accurately and may be in denial about their symptoms. They may also start withdrawing from family or friends because socialization becomes difficult. At this stage, a physician can detect clear cognitive problems during a patient interview and exam.	Average duration of this stage is 2 years.
Mid-stage	Stage 5: Moderately Severe Cognitive Decline	People in this stage have major memory deficiencies and need some assistance to complete their daily living activities (dressing, bathing, preparing meals, etc.). Memory loss is more prominent and may include major relevant aspects of current lives. For example, people may not remember their address or phone number and may not know the time or day or where they are.	Average duration of this stage is 1.5 years.
Mid-stage	Stage 6: Severe Cognitive Decline (Middle Dementia)	People in Stage 6 require extensive assistance to carry out their Activities of Daily Living (ADLs). They start to forget names of close family members and have little memory of recent events. Many people can remember only some details of earlier life. Individuals also have difficulty counting down from 10 and finishing tasks. Incontinence (loss of bladder or bowel control) is a problem in this stage. Ability to speak declines. Personality / emotional changes, such as delusions (believing something to be true that is not), compulsions (repeating a simple behavior, such as cleaning), or anxiety and agitation may occur.	Average duration of this stage is 2.5 years
Late-stage	Stage 7: Very Severe Cognitive Decline (Late Dementia)	People in this stage have essentially no ability to speak or communicate. They require assistance with most activities (e.g., using the toilet, eating). They often lose psychomotor skills. For example, the ability to walk.	Average duration of this stage is 1.5 to 2.5 years.

1. From "Integrating a Palliative Approach: Essentials for Personal Support Workers, 2nd Ed, 2019, K. Murray. All Rights Reserved 2023

2. Reisberg B, Ferris SH, Leon MJ, et al. The global deterioration scale for assessment of primary degenerative dementia. Am J Psychiatry. 1982; 139:1136-1139.