

## WHAT IS DEMENTIA?

**Dementia** refers to a clinical syndrome characterized by progressive cognitive decline that interferes with the ability to function independently.<sup>1</sup> Symptoms of dementia are gradual, persistent, and progressive. Individuals suffering from dementia experience changes in cognition, function, and behavior. Clinical presentation of dementia varies greatly among individuals, and the cognitive deficits it causes can present as memory loss, communication and language impairments, agnosia (inability to recognize objects), apraxia (inability to perform previously learned tasks), and impaired executive function (reasoning, judgement, and planning). Cognitive impairment stems from injury to the cerebral cortex caused by synaptic failure, inflammation, or changes in cerebral metabolism.

The term “dementia” was eliminated from all diagnoses, replaced with “neurocognitive disorder” in 2013 with the release of the *Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> Edition*. Criteria for neurocognitive disorders are based on alterations in the defined domains of complex attention, executive function, learning and memory, language, perceptual motor, and social cognition.<sup>2</sup>

## SIGNS & SYMPTOMS

**Mental status assessments:** Assessment of a patient’s mental and cognitive status with mental status examinations to evaluate cognitive function serves as a baseline for later comparison to document declining function.<sup>2</sup> The following are some of the most frequently used mental status examinations.

Mini-Mental Status Examination (MMSE®)	Modified Boston Naming Test (BNT)	Short Portable Mental Status Questionnaire (SPMSQ)
Montreal Cognitive Assessment (MoCA)	Mini-Cog®	Memory Orientation Screening Test (MOST®)

**Functional assessments:** Understanding a person’s functional status, abilities, and disabilities helps palliative care providers to focus on care most needed at a particular stage of illness.<sup>2</sup> The following are some of the most frequently used functional assessments.

Clinical Dementia Rating (CDR)	Functional Assessment Staging Tool (FAST)	Advanced Dementia Prognostic Tool (ADEPT)
Global Deterioration Scale (GDS)	Mortality Risk Index (MRI)	

In neurocognitive disorders, the brain shrinks more extensively compared to natural contractions of the brain due to aging. This can result in marked changes of appearance in specific areas of the brain. Changes can be detected in the cortical, subcortical, or mixed areas with neuroimaging. They can result from numerous causes, including Alzheimer’s disease, multiple strokes, infections in the brain, severe brain injury, and thyroid deficiencies.<sup>2</sup>

**Psychiatric symptoms:** delusions, depressive symptoms, hallucinations, and paranoia<sup>2</sup>

**Behavioral symptoms:** aggression, rummaging, and agitation, including restlessness and anxiety, screaming, disinhibition, swearing, pacing, walking about or meandering, and picking<sup>2</sup>

**Mood symptoms:** anxiety, apathy, depression, euphoria, and irritability<sup>2</sup>

**Physical symptoms:** loss of appetite and sleep disturbances<sup>2</sup>

Common Dementia Types <sup>2</sup>	Cognitive Deficits and Clinical Features <sup>2</sup>
<p><b>Alzheimer’s disease</b> (most common)</p> <p><b>Average age of onset:</b> 65 years</p>	<p>Early memory loss</p> <p>Impaired executive function</p> <p>Progressive decline</p> <p>Loss of orientation</p> <p>Personality and behavioral changes</p> <p>Memory impairment</p> <p>Hallucinations</p>
<p><b>Vascular dementia</b> (second most common)</p> <p><b>Average age of onset:</b> 60–70 years</p>	<p>Cognitive deficits, variable with site</p> <p>Impaired language</p> <p>Impaired executive function</p> <p>Stepwise progression</p> <p>Mood swings</p> <p>Stroke</p> <p>Depression</p> <p>Memory impairment</p> <p>Hallucinations</p>

<p><b>Dementia with Lewy bodies</b></p> <p><b>Average age of onset:</b> 50 years or older</p>	<p>Cognitive deficits, variable</p> <p>Cognitive decline</p> <p>Hallucinations</p> <p>Parkinsonian symptoms</p> <p>Falls</p> <p>Memory impairment</p> <p>Rapid eye movement (REM) sleep behavior disorder</p>	
<p><b>Frontotemporal dementia</b></p> <p><b>Average age of onset:</b> 45–65 years</p>	<p>Personality and behavioral changes</p> <p>Disinhibition</p> <p>Lack of empathy</p> <p>Oral fixations</p> <p>Repetitive actions</p>	
<p><b>Alcohol-induced dementia</b> ( &gt; 150 ml of ETOH per day)</p>	<p>Age, length of alcohol abuse, and amount affect cognitive decline.</p> <p>After exclusion of other forms of dementia, cognitive decline continues after alcohol discontinuation.</p> <p>Amnesia</p> <p>Memory disturbances</p> <p>Impaired executive function</p>	
<p><b>Human immunodeficiency virus (HIV) dementia</b></p>	<p>Documented HIV infection</p> <p><b>Early stage:</b></p> <p>Gait disturbance</p> <p>Impaired concentration and attention</p> <p>Impaired verbal memory</p> <p>Mental slowing</p> <p>Difficulty with calculations and abstractions</p> <p>Visuospatial memory impairment</p> <p>Lack of visuomotor coordination</p> <p>Difficulty with task sequencing</p>	<p><b>Late stage:</b></p> <p>Impaired decision-making, judgment, and reasoning</p> <p>Confusion/disorientation</p> <p>Aphasia</p> <p>Autism</p> <p>Global cognitive impairment and mutism</p> <p>Behavioral disturbances such as psychosis, mania, and disinhibition</p> <p>Secondary delirium with hallucinations/delusions</p>

**Initial laboratory/diagnostic testing** can rule out reversible causes of cognitive impairment.

**Review goals of care** with the patient and family, taking into consideration the extent of the disease, other symptoms, whether palliative treatment is still in process, age, developmental and emotional status, and physical location of the patient.<sup>3</sup>

**Discuss the benefits and burdens** of treatment to reduce frequency and intensity of symptoms caused by dementia. Consider the patient’s and family’s goals and wishes, as well as their definition of quality of life, when evaluating treatment options.<sup>3</sup>

**Advanced care planning:** Designate a surrogate decision-maker for health care, have patient and family complete an advance directive or living will, and prepare out-of-hospital orders for life-sustaining measures. Advanced care planning is important due to the patient’s progressive cognitive decline and gradual loss of decision-making ability.

**INTERVENTIONS**

Currently, there are no medications or treatments to halt or alter the eventual progression of dementia. Some medications may alleviate symptoms, diminish disruptive behaviors, or improve cognition. The foundation of dementia care is to provide an environment that respects a patient’s personhood; optimizes the individual’s cognitive and functional abilities; supports the person’s remaining abilities; and minimizes physical, emotional, and spiritual distress.<sup>2</sup>

NONPHARMACOLOGICAL INTERVENTIONS <sup>2</sup>	PHARMACOLOGICAL INTERVENTIONS <sup>2</sup>
<p>Focus on person-centered care, a supportive environment, and methods to support memory. Identify unmet palliative care needs such as behavioral concerns, pain, and difficult decisions regarding treatment and care placement.</p> <p>The plan of care may include:</p> <ul style="list-style-type: none"> <li>• Reminiscence therapy and multisensory stimulation to engage cognitive aspects of the brain</li> <li>• Continued socialization to prevent distress (agitation), boredom, and depression</li> <li>• Healing touch, music therapy, and massage to alleviate distress</li> <li>• Physical exercise to decrease distress and reduce repetitive movements</li> </ul>	<p>Nonpharmacological interventions should be used first. Resort to pharmacological interventions only when the former interventions are ineffective or fail.</p> <p><b>Alzheimer’s disease:</b> cholinesterase inhibitors, N-methyl-D-aspartate (NMDA) receptor antagonists</p> <p><b>Vascular dementia:</b> beta blockers, antiplatelet therapy</p> <p><b>Lewy body dementia:</b> selective serotonin reuptake inhibitors (SSRIs), beta blockers</p> <p><b>Frontotemporal dementia:</b> No medications have been approved by the U.S. Food and Drug Administration. Focus on palliating symptoms.</p> <p><b>Alcohol-induced dementia:</b> alcohol cessation, concomitant lactulose therapy, thiamine, niacin, nutritional supplements</p> <p><b>HIV dementia:</b> antiretroviral medications, discontinuation of antiviral therapy at the end of life</p>

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<ul style="list-style-type: none"> <li>• Rote and purposeful activities (folding clothes or towels, stacking things, looking through the pages of a picture book), which can be soothing and stimulating</li> </ul>	<p><b>Dementia symptom management:</b></p> <p>Depression/agitation: SSRIs, serotonin-norepinephrine reuptake inhibitors (SNRIs)</p> <p>Sleep disturbances: sedatives</p> <p>Delirium: antipsychotics</p> <p>Agitation/aggression/anxiety: anxiolytics, anticonvulsants</p>

## FAMILY & TEAM DISCUSSIONS

**Patient and family education and support may include the following.<sup>1,2,3</sup>**

- Explore, support, and educate the family about the responsibilities of caregiving, caregiver fatigue and burden, and caregiver coping and support.
- Instruct on underlying etiologies of dementia, treatment options, medications, and anticipated effects.
- Clarify the intent of treatments, anticipate the needs of the patient and family, and involve caregivers in the therapy process when appropriate.
- Explore realistic goals and expectations. Provide reassuring education on continued management strategies to allay fears.
- Educate on appropriate nonpharmacological strategies and safety.
  - a. Provide ongoing instruction on medication effects and side effects, as they may contribute to relief or exacerbation of dementia symptoms.
  - b. Consider tapering or discontinuing medication if appropriate.

### **Interprofessional Team:**

Successful interventions in caring for patients with dementia benefit from multiple perspectives to treat physical, social, psychological, and spiritual aspects of care.

## GOALS OF CARE DOCUMENTATION EXAMPLE

**76 yr old male with Alzheimer's disease**, current FAST score of 7C, PPS score of 40%, and progressive functional decline over the past year. Six months ago, the patient's baseline was documented as FAST 7B and PPS 60%. He has had a progressive decline, including three hospitalizations secondary to aspiration pneumonia and bacteremia in the past

three months. This has contributed to increased weakness and fatigue, and he is no longer able to ambulate independently. He requires maximal assist x 1 for all activities of daily living and is dependent on his daughter for all independent activities of daily living. He moved in with his daughter three months ago due to increased personal care needs. The daughter has taken a leave of absence from work until she can find more assistance in the home. He is without hallucinations, changes in baseline behavior, or uncontrolled symptoms this visit.

We discussed healthcare goals, treatments, values, and beliefs. The patient previously stated he would prefer to die at home with family. We discussed preferences for life-sustaining treatments and advance directives. Following a discussion about goals of care, the daughter is requesting hospice care for the patient and a change in code status from full code to do not resuscitate/do not intubate, comfort measures only, limited use of antibiotics for comfort, and no hydration or artificial nutrition by tube. A POLST form (Physicians Orders for Life-Sustaining Treatment) was reviewed, completed, and signed by the patient's daughter, then sent to the primary care physician for collaboration and signature to move forward with hospice care.

### DESIRED NURSING OUTCOMES

- Improve physical, psychological, social, and spiritual well-being of patients and caregivers suffering from the distressing symptoms of dementia.
- Improve quality of life by exploring patient and family beliefs and expectations related to the dementia experience.
- Improve communication among the provider, patient, and caregiver to encourage reporting of changes in cognitive, functional, or social behaviors; exacerbation of baseline symptoms; and what improves dementia symptoms.

### REFERENCES

1. Duong S, Patel T, Chang F. Dementia. *Canadian Pharmacists Journal*. 2017;150(2):118-129. doi: 10.1177/1715163517690745.
2. White CW. Neurocognitive disorders. In Whitehead P, Dahlin C, eds. *Compendium of Nursing Care for Common Serious Illnesses*. 3rd ed. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2019.
3. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*. 4th ed. Richmond, VA: National Coalition for Palliative Care; 2018.