



# Dementia Aware<sup>®</sup>

## Handouts

Inspire, Educate & Empower Dementia Caregivers

[www.tamcummings.com](http://www.tamcummings.com)



# Cancer vs Dementia

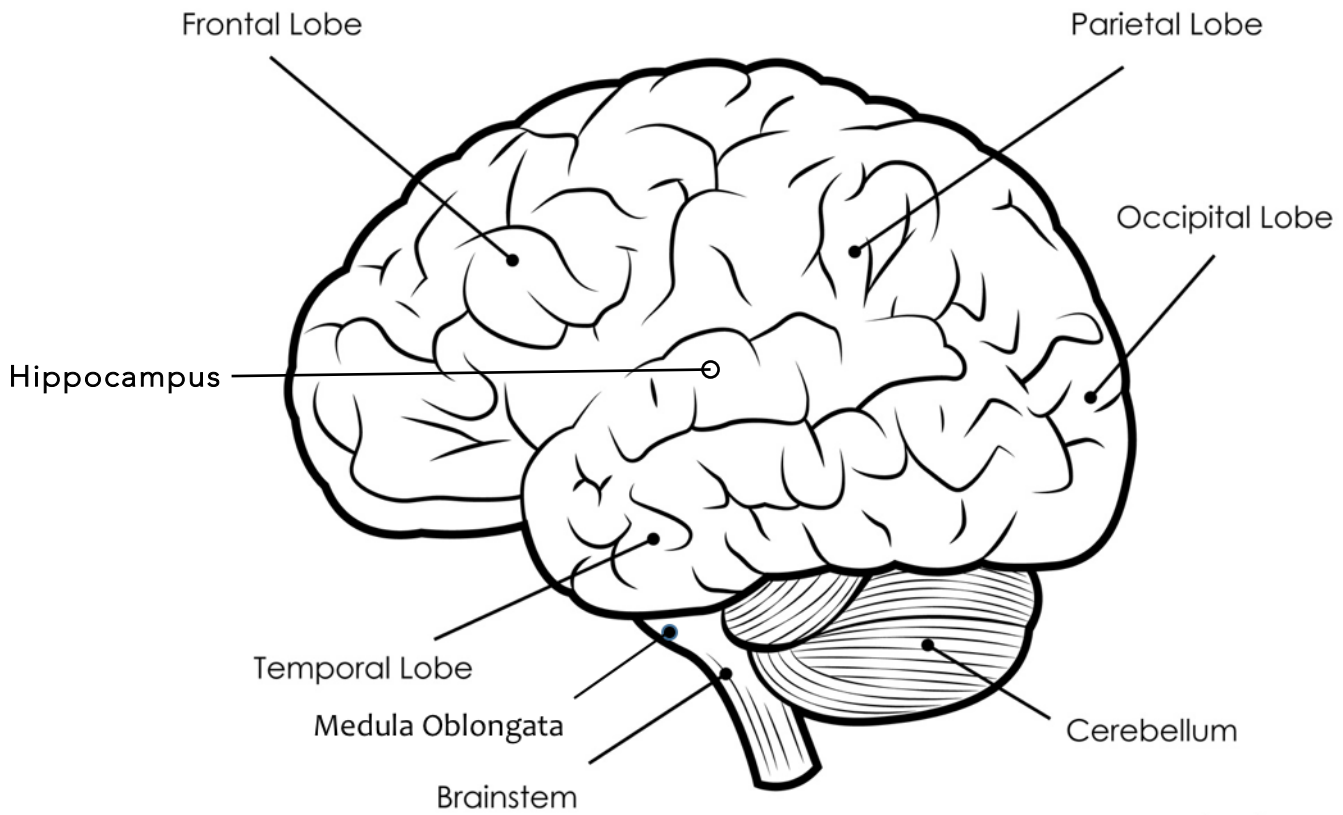


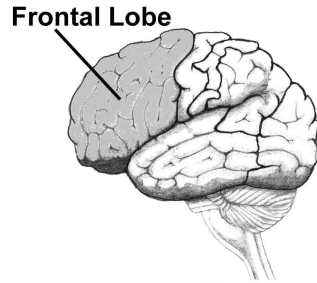
## Eight Most Common Dementias

- 1 Mixed Dementia
- 2 Alzheimer's
- 3 Vascular Dementia
- 4 Lewy Bodies Dementia
- 5 FrontoTemporal Dementia
- 6 Parkinson's Disease Dementia
- 7 Wernicke-Korsakoff Syndrome
- 8 Huntington's Dementia



# Lobes of the Brain





Frontal Lobe functions: abstract thought, personality, attention, behavior, sexual behavior, emotional expression, initiation, concentration, organization, motor planning, self-monitoring, awareness of ability, coordination of movement, creative thought, imagination, impulse control, inhibition, initiative, intellect, judgment, memory, problem solving, produce and understand language, rational thought, reflection, speech and some emotion.

### **Symptoms of Impairment:**

- Changes in personality & social behavior
- Loss of spontaneity in interactions
- Loss of flexibility in thinking
- Sequencing – doing tasks in the right order
- Easily distracted
- Mood swings
- Diminished abstract reasoning
- Difficulty with problem solving
- Language difficulties – word usage and word finding
- Loss of simple movement abilities of various body parts
- Perseveration – repeating actions or comments without awareness

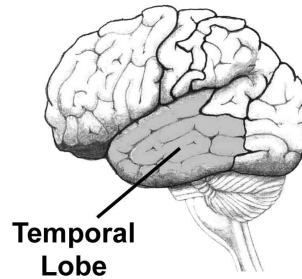
### **Which of the A's of the Dementia do you usually see here?**

**Anger, apathy, attention, anxiety** – these are often witnessed as the person with dementia begins to react her brain's failure to function normally.

**Amnesia** – the inability to use or retain memory, including short term and long term memory. The person may constantly repeat questions such as “Where am I?” and “Who are you?” and “When are we going to eat?” or accuse the caregiver of stealing or being an imposter. This type of behavior can continue for hours at a time. This process occurs from damage to the Frontal lobes and the Hippocampus. The Frontal lobes store memory, personality, cognition, impulse control, speech, attention, rational thought, imagination and judgment. The Hippocampus allows us to learn any new information, such as being able to remember the answer to the question “Where are we going?”

This is usually the first area of change noticed by families and the “A” which has most likely caused verbal or physical abuse within the family structure.

In this beginning level of Amnesia, the person with dementia does not look ill, so the confusion and inability to remember can appear to be purposeful and is often interpreted by us as just “annoying” behavior.



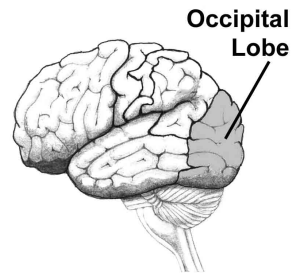
**Temporal Lobe functions:** auditory memories, cursing, fear, hearing, understanding, language, music, awareness, sense of identity, singing, some behavior and emotion, feelings, organization and sequencing, smell, some visual pathways, speech and visual memories (faces, places, foods, objects), memory, learning, information retrieval.

**Symptoms of Impairment:**

- Difficulty remembering names and faces
- Difficulty with Identification and verbalization of objects
- Difficulty understanding spoken word
- Concentration difficulties
- Aggressive behavior
- Short-term memory loss
- Long-term memory interference
- Change in sexual interest
- Persistent talking
- Difficulty locating objects in environments
- Inability to categorize objects
- Religiosity
- Seizure disorders, auras, strange reveries

**Which of the A's of the Dementia do you usually see here?**

**Aphasia** – the inability to use or understand language. The person will use the wrong word, or complete a story with phrases from another story, or provide a lengthy description of an item because he/she cannot find the right word. He/she may call family members by the wrong name, which increases the family's anxiety and concern. This word finding difficulty will increase until all language use is lost. This is associated with damage to the Temporal lobes and the Frontal lobes. The Temporal lobes control hearing, language and smell. The left lobe holds formal language and the right lobe controls automatic speech (yes and no), singing and cursing. The left lobe is generally destroyed first leaving the person with dementia the ability to communicate with swearing and singing.



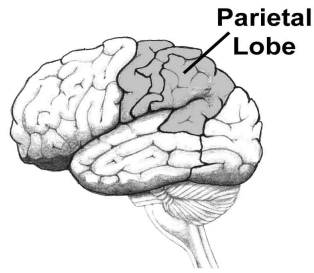
**Occipital Lobe functions:** depth perception, visual reception area, reading, visual acuity, and visual interpretation.

**Symptoms of Impairment:**

- Impaired vision
- Front visual fields impacted
- Loss of 3D to 1D
- Possible loss of vision in left eye
- Peripheral vision field reduced
- Misinterpretation of persons, objects, and environment

**Which of the A's of the Dementia do you usually see here?**

**Agnosia** -- the inability to recognize or use common objects or people. The person may become lost in a familiar place because he/she doesn't recognize the items that alert us to our surroundings. He/she may confuse a fork with a spoon, a toothbrush with a hairbrush or toothpaste with denture cream. Eventually the ability to recognize objects is lost completely. The person may also confuse a son with a husband or a father or an uncle, or a daughter may be confused with a mother or an aunt or a grandmother. This process is associated with increased damage to the Frontal lobes, the Occipital lobes (visual association, distance and depth perception) and the Temporal lobes.



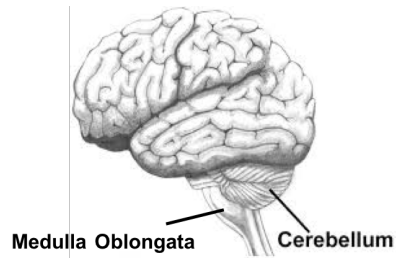
**Parietal Lobes functions:** appreciation of form through touch, body's temperature perception, sensory combination and comprehension. writing and reading, some visual functions, taste and touch, math calculations, academic skills, visual perception, spatial perception, differentiation of shape, size, and color, sense of touch, taste, smell.

**Symptoms of Impairment:**

- Difficulty naming objects
- Difficulty writing words
- Difficulty multitasking
- Problems with reading
- Poor hand-eye coordination
- Confusion left-right orientation
- Difficulty with math and drawing
- Poor visual perception- inability to focus visual attention
- Lack of awareness of body and space

**Which of the A's of the Dementia do you usually see here?**

Apraxia – the inability to use or coordinate purposeful muscle movement or coordination. In the early stages the person may reach for an item and miss it. He may have difficulty catching a ball or clapping his hands. The floor may appear to be moving to this person and balance becomes affected, increasing the risk for falls and injury. In time, this loss of ability to move affects the Activities of Daily Living (transferring, sleeping, ambulating, toileting, bathing, grooming, dressing and eating). In the end stage, the person is not able to properly chew or swallow food, increasing the risk of choking or aspiration. This is linked to damage to Parietal lobes (pain, touch, temperature and pressure, sensory perception) and the Cortex (skilled movement) and the Occipital lobes.



**Cerebellum functions:** coordination and control of coordinated movement, balance and muscle tone, equilibrium, some memory of reflex motor acts

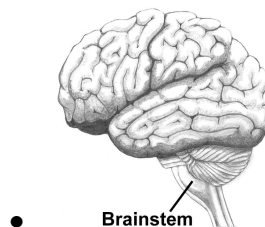
**Symptoms of Impairment:**

- Tremors
- Involuntary eye movements
- Ataxia – lack of coordination
- Weak muscles
- Inability to judge distance and when to stop
- Inability to perform rapid altering movement
- Slurred speech

**Medulla Oblongata functions:** helps regulate breathing, heart and blood vessel function, digestion, sneezing, swallowing, respiration and circulation.

**Symptoms of Impairment:**

- Communication between the brain and the spinal cord is disrupted.
- In chronic alcohol use, significant synapse loss and axonal impairment makes the brain susceptible to injury.
- Swallowing food and liquids
- 



**Brain Stem functions:** swallowing, plays a role in heart rate, reflexes to sight and sound, sweating, blood pressure, digestion, temperature, levels of alertness, ability to sleep, and balance

**Symptoms of Impairment:**

- Swallowing food and liquids
- Dizziness and nausea
- Sleeping difficulties
- Decreased vital capacity in breathing
- Problems with balance and movement
- Difficulty with organization and/or perception of the environment

## PHYSICAL SELF-MAINTENANCE SCALE (ACTIVITIES OF DAILY LIVING, OR ADLs)

In each category, circle the item that most closely describes the person's highest level of functioning and record the score assigned to that level (either 1 or 0) in the blank at the beginning of the category.

A. Toilet		
1.	Care for self at toilet completely; no incontinence	1
2.	Needs to be reminded, or needs help in cleaning self, or has rare (weekly at most) accidents	0
3	Soiling or wetting while asleep more than once a week	0
4.	Soiling or wetting while awake more than once a week	0
5.	No control of bowels or bladder	0
B. Feeding		
1.	Eats without assistance	1
2.	Eats with minor assistance at meal times and/or with special preparation of food, or help in cleaning up after meals	0
3	Feeds self with moderate assistance and is untidy	0
4.	Requires extensive assistance for all meals	0
5.	Does not feed self at all and resists efforts of others to feed him or her	0
C. Dressing		
1.	Dresses, undresses, and selects clothes from own wardrobe	1
2.	Dresses and undresses self, with minor assistance	0
3	Needs moderate assistance in dressing and selection of clothes.	0
4.	Needs major assistance in dressing, but cooperates with efforts of others to help	0
5.	Completely unable to dress self and resists efforts of others to help	0
D. Grooming (neatness, hair, nails, hands, face, clothing)		
1.	Always neatly dressed, well-groomed, without assistance	1
2.	Grooms self adequately with occasional minor assistance, eg, with shaving	0
3	Needs moderate and regular assistance or supervision with grooming	0
4.	Needs total grooming care, but can remain well-groomed after help from others	0
5.	Actively negates all efforts of others to maintain grooming	0
E. Physical Ambulation		
1.	Goes about grounds or city	1
2.	Ambulates within residence on or about one block distant	0
3	Ambulates with assistance of (check one)	
4.	a ( ) another person, b ( ) railing, c ( ) cane, d ( ) walker, e ( ) wheelchair	0
5.	1. Gets in and out without help. 2. Needs help getting in and out	
6.	Sits unsupported in chair or wheelchair, but cannot propel self without help	0
7.	Bedridden more than half the time	0
F. Bathing		
1.	Bathes self (tub, shower, sponge bath) without help.	1
2.	Bathes self with help getting in and out of tub.	0
3	Washes face and hands only, but cannot bathe rest of body	0
4.	Does not wash self, but is cooperative with those who bathe him or her.	0
5.	Does not try to wash self and resists efforts to keep him or her clean.	0
*****For scoring interpretation and source, see note following the next instrument.		

## INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADLs)

In each category, circle the item that most closely describes the person's highest level of functioning and record the score assigned to that level (either 1 or 0) in the blank at the beginning of the category.

<b>A.</b>	<b>Ability to Use Telephone</b>	
1.	Operates telephone on own initiative; looks up and dials numbers.	1
2.	Dials a few well-known numbers.	1
3.	Answers telephone, but does not dial.	1
4.	Does not use telephone at all.	0
<b>B.</b>	<b>Shopping</b>	
1.	Takes care of all shopping needs independently.	1
2.	Shops independently for small purchases.	0
3.	Needs to be accompanied on any shopping trip.	0
4.	Completely unable to shop.	0
<b>C.</b>	<b>Food Preparation</b>	
1.	Plans, prepares, and serves adequate meals independently.	1
2.	Prepares adequate meals if supplied with ingredients.	0
3.	Heats and serves prepared meals or prepares meals, but does not maintain adequate diet.	0
4.	Needs to have meals prepared and served.	0
<b>D.</b>	<b>Housekeeping</b>	
1.	Maintains house alone or with occasional assistance (e.g., heavy-work domestic help).	1
2.	Performs light daily tasks such as dishwashing, bed making.	1
3.	Performs light daily tasks, but cannot maintain acceptable level of cleanliness.	1
4.	Needs help with all home maintenance tasks.	1
5.	Does not participate in any housekeeping tasks.	0
<b>E.</b>	<b>Laundry</b>	
1.	Does personal laundry completely.	1
2.	Launders small items; rinses socks, stockings, etc.	1
3.	All laundry must be done by others.	0
<b>F.</b>	<b>Mode of Transportation</b>	
1.	Travels independently on public transportation or drives own car.	1
2.	Arranges own travel via taxi, but does not otherwise use public transportation.	1
3.	Travels on public transportation when assisted or accompanied by another.	1
4.	Travel limited to taxi or automobile with assistance of another.	0
5.	Does not travel at all.	0
<b>G.</b>	<b>Responsibility for own Medication</b>	
1.	Is responsible for taking medication in correct dosages at correct time.	1
2.	Takes responsibility if medication is prepared in advance in separate dosages.	1
3.	Is not capable of dispensing own medication.	0
<b>E.</b>	<b>Ability to Handle Finances</b>	
1.	Manages financial matters independently (budgets, writes checks, pays rent and bills, goes to bank); collects and keeps track of income	1
2.	Manages day-to-day purchases, but needs help with banking, major purchase	1
3.	Incapable of handling money	0
<b>Score:</b>		___

## GERIATRIC DEPRESSION SCALE (GDS, SHORT FORM)

Choose the best answer for how you felt over the past week.

1.	Are you basically satisfied with your life?	yes/no	
2.	Have you dropped many of your activities and interests?	<b>yes/no</b>	
3.	Do you feel that your life is empty?	<b>yes/no</b>	
4.	Do you often get bored?	<b>yes/no</b>	
5.	Are you in good spirits most of the time?	yes/no	
6.	Are you afraid that something bad is going to happen to you?	<b>yes/no</b>	
7.	Do you feel happy most of the time?	yes/no	
8.	Do you often feel helpless?	<b>yes/no</b>	
9.	Do you prefer to stay at home, rather than going out and doing new things?	<b>yes/no</b>	
10.	Do you feel you have more problems with memory than most?	<b>yes/no</b>	
11.	Do you think it is wonderful to be alive now?	yes/no	
12.	Do you feel pretty worthless the way you are now?	<b>yes/no</b>	
13.	Do you feel full of energy?	yes/no	
14.	Do you feel that your situation is hopeless?	<b>yes/no</b>	
15.	Do you think that most people are better off than you are?	<b>yes/no</b>	
<b>Score:</b>			

### Instructions:

Take this test twice.

**First** - Take the test for your loved one based on their behaviors during the last six months. Use the blank column on the right hand side to record your score. If the answer to the question matches the bold answer place a "1" in the right hand column. At the end of the test, total the score. A score above 5 is a positive test for depression.

**Second** - Now take the test for yourself. A score above 5 is a positive test for depression.

<b>STAGE 1 - NORMAL AGING</b>	
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	No cognitive changes evident. Normal aging, normal brain function.
<b>STAGE 2 - EARLY STAGE</b>	
Mild Cognitive Impairment (MCI)	Minimal brain tissue loss
Stage thought to last - unknown amount of time	Ages 40 to 55/60
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Fleeting moments of cognitive loss
<input type="checkbox"/>	Recovers relatively quickly from mistakes, may correct self
<input type="checkbox"/>	Misplaces familiar objects
<input type="checkbox"/>	Forgets names he/she knows well
<input type="checkbox"/>	No problems completing tasks or at social functions
<input type="checkbox"/>	Exhibits appropriate concern over memory function
<input type="checkbox"/>	Vacillates between seeking medical care and ignoring symptoms
<input type="checkbox"/>	Functions effectively at work and at home
<input type="checkbox"/>	Highly functional social skills
<input type="checkbox"/>	Requires complete cognitive testing to determine illness
<input type="checkbox"/>	Responds to cognitive therapy
<input type="checkbox"/>	Scores well on orientation test
<input type="checkbox"/>	Amnesia <sup>1</sup> beginning to be expressed
<b>STAGE 3 - MIDDLE STAGE</b>	
Beginning Dementia	Minimal brain tissue loss
Stage thought to last 1 - 4 years	
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Memory deficit evident in intensive interview
<input type="checkbox"/>	Attempts to conceal deficits and denies any cognition difficulties
<input type="checkbox"/>	Expresses concern regarding deficits (mild/moderate anxiety)
<input type="checkbox"/>	Problems performing in demanding situations (work or social)
<input type="checkbox"/>	Co-workers/family members beginning to be aware of increasing challenges
<input type="checkbox"/>	Can get lost traveling to new areas
<input type="checkbox"/>	Exhibits signs of cognition but may retain little new information
<input type="checkbox"/>	Name/word finding difficulty more frequent
<input type="checkbox"/>	Challenged to remember new names
<input type="checkbox"/>	May appear depressed
<input type="checkbox"/>	Demonstrates high social skill level
<input type="checkbox"/>	Uses humor to avoid answering questions
<input type="checkbox"/>	No noticeable physical changes, but may begin stumbling or falling or sleeping excessively
<input type="checkbox"/>	Beginning to skip steps in tasks
<input type="checkbox"/>	Able to score well on orientation test, but not on cognition exam
<input type="checkbox"/>	At times appears befuddled or confused
<input type="checkbox"/>	Amnesia <sup>1</sup> and Aphasia <sup>2</sup> present - needs new information repeated

<b>STAGE 4 - MIDDLE STAGE</b>	
Moderate Dementia	4 ounces brain tissue loss
Stage thought to last 1- 4 years	Equivalent of 12 years old to adulthood
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Decreased knowledge of current and recent events
<input type="checkbox"/>	Memory deficits regarding personal history, may look to spouse to answer questions
<input type="checkbox"/>	Decreased ability to perform serial subtractions (100 - 7, 93 - 7, 86 -7, etc.)
<input type="checkbox"/>	Difficulty with immediate recall - for example, what time is doctor's appointment?
<input type="checkbox"/>	Difficulty with complex tasks such as driving, finances, shopping, bathing
<input type="checkbox"/>	Denial of deficits, with or with out agitation and annoyance
<input type="checkbox"/>	Withdraws from challenging situations - refuses to complete tasks, may make excuses
<input type="checkbox"/>	Increased anxiety/frustration over abilities or loss of abilities
<input type="checkbox"/>	Difficulty telling jokes, stories - starting to mix up stories
<input type="checkbox"/>	Decreased facial affect (emotion on face)
<input type="checkbox"/>	Increased depressive symptoms, possibly Atypical <sup>8</sup> : anxiety, anger, agitation, aggression
<input type="checkbox"/>	May hesitate when trying to correctly identify family members or close friends
<input type="checkbox"/>	Can have normal cognition for hours or days, then become quite confused
<input type="checkbox"/>	May become lost in tasks
<input type="checkbox"/>	Greater language challenges, word-finding difficulty
<input type="checkbox"/>	Begins to have stumbles or falls
<input type="checkbox"/>	Begins to shadow caregiver and may begin to have difficulty with ADLs <sup>6</sup> or IADLs <sup>7</sup>
<input type="checkbox"/>	May begin keeping lists of family names, phone numbers, etc.
<input type="checkbox"/>	Exhibits greater desire for sweet foods
<input type="checkbox"/>	May score well on orientation test, dementia evident on cognition exam
<input type="checkbox"/>	Amnesia <sup>1</sup> , Aphasia <sup>2</sup> , Agnosia <sup>3</sup> and Anosognosia <sup>4</sup> present, some paranoia present
<b>EARLY STAGE 5 - LATE STAGE</b>	
Moderately Severe Dementia	1/2 to 1 pound of brain tissue loss
Stage thought to last 1- 3 years	Equivalent of 12 - 8 year old
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Disorientation to time (date, day of week, season, etc.) or place
<input type="checkbox"/>	Immediate memory relatively intact - knows self and family
<input type="checkbox"/>	May need assistance choosing and layering clothing, but denies need for IADL/ADL
<input type="checkbox"/>	May crave sweets over other foods
<input type="checkbox"/>	Begins to have falls
<input type="checkbox"/>	Hunting and gathering stage, wanders from room to room collecting items
<input type="checkbox"/>	Urinary incontinence begins – monthly to weekly to daily
<input type="checkbox"/>	Wears clothing appropriately (hearing aid, glasses, carries purse)
<input type="checkbox"/>	*Feeds self (may need meal set-up)
<input type="checkbox"/>	Sleep disturbances, excessive sleeping or napping
<input type="checkbox"/>	Can score well on an orientation test, but not a cognition test
<input type="checkbox"/>	Wanders looking for a way out (purposeful wandering/ Sundowning)
<input type="checkbox"/>	Follows simple instructions for ADLs, verbal cues needed for tasks
<input type="checkbox"/>	Unexplained tearfulness or extreme laughter
<input type="checkbox"/>	Catastrophic reactions - may be easily annoyed, agitated, verbally or physically aggressive
<input type="checkbox"/>	Hallucinations, accusatory behavior, excessive sleeping - report to doctor
<input type="checkbox"/>	Amnesia <sup>1</sup> , Aphasia <sup>2</sup> , Agnosia <sup>3</sup> , Anosognosia <sup>4</sup> and Apraxia <sup>5</sup> evident to outsiders

<b>LATE STAGE 5 - LATE STAGE</b>	
Moderately Severe Dementia	Equivalent to 8 - 4 year old
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	May begin having chronic Urinary Tract Infections (UTIs)
<input type="checkbox"/>	Appears severely depressed with increased loss of facial affect
<input type="checkbox"/>	Increased fall risks, may not recognize severity of the fall especially to the head
<input type="checkbox"/>	Coordinated movement/function beginning to be affected
<input type="checkbox"/>	Begins to be lost in current time
<input type="checkbox"/>	Difficulty recognizing self in a mirror
<input type="checkbox"/>	Challenged to recall family members, may confuse daughter with mother, etc.
<input type="checkbox"/>	Accuses family members, caregivers of theft, infidelity, lying, increased paranoia possible
<input type="checkbox"/>	Automatic "yes/no" speech functions, but without understanding
<input type="checkbox"/>	May begin using curse words as temporal lobes become damaged
<input type="checkbox"/>	Changes in visual perception increasing, bumps into objects, peripheral vision damaged
<input type="checkbox"/>	Difficulty interpreting background noise
<input type="checkbox"/>	Challenged to perform rehab for injuries, may appear stubborn to therapist/family
<input type="checkbox"/>	Cannot give accurate information, verbal skills damaged
<input type="checkbox"/>	Caregivers may confuse behavior for purposeful action – lying, etc.
<input type="checkbox"/>	Physical appearance beginning to be affected
<input type="checkbox"/>	Pilling or rubbing hand motions common, may enjoy folding items
<b>STAGE 6 - LATE STAGE</b>	
Severe Dementia	1 - 1 ½ pounds of brain tissue loss
Stage thought to last 1- 3 years	Equivalent to 4 – 2 year old
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Unable to recall most recent events
<input type="checkbox"/>	Repetitiveness in motion or speech or memory
<input type="checkbox"/>	May be in constant motion, wanders/walks for hours
<input type="checkbox"/>	Removes/won't wear clothing appropriately
<input type="checkbox"/>	Disregards eyeglasses, dentures, hearing aids (Agnosia <sup>3</sup> ) - may throw them away
<input type="checkbox"/>	Refuses to change clothing, unable to complete IADLs and a few ADLs
<input type="checkbox"/>	*Feeds self with set-up, cues and assistance
<input type="checkbox"/>	Bowel incontinence begins
<input type="checkbox"/>	Sleep disturbances - may increase sleep, may require little sleep
<input type="checkbox"/>	Catastrophic reactions may occur - great resistance to care giving, bathing
<input type="checkbox"/>	Purposeless wandering/Sun-downing (wandering without an agenda)
<input type="checkbox"/>	Cannot complete a two-stage command, such as pick up a piece of paper and fold it
<input type="checkbox"/>	Apraxia <sup>5</sup> advanced, gait altered (small shuffling steps)
<input type="checkbox"/>	Aphasia <sup>2</sup> increased, great language loss, uses bits and pieces of words or sounds
<input type="checkbox"/>	Weight loss beginning, may lose ½ or more of body weight
<input type="checkbox"/>	Difficult to engage with caregiver, challenged to initiate conversation
<input type="checkbox"/>	Disheveled appearance
<input type="checkbox"/>	Fall risk continues to increase until wheelchair bound, risk for fractured bones increases
<input type="checkbox"/>	Difficult to perform rehab for injuries
<input type="checkbox"/>	Almost total loss of facial affect
<input type="checkbox"/>	May suddenly use complete sentence, then only words or sounds

<b>STAGE 7 - LATE STAGE</b>	
Very Severe Dementia	1 ½ - 2 pounds of brain tissue loss
Stage thought to last 1- 2 years	Equivalent to 2 year old - Infant
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Frequently no speech at all – mostly grunting or word sounds
<input type="checkbox"/>	*Cannot feed self --- chipmonking or holding food in cheeks, high risk for choking
<input type="checkbox"/>	Unable to sit up independently, unable to hold head up
<input type="checkbox"/>	Loss of basic psychomotor skills (unable to walk w/o assistance)
<input type="checkbox"/>	Hyper oral (may put everything in mouth)
<input type="checkbox"/>	Requires total care, displays great muscular flexation, hands curl, arms and legs pull up
<input type="checkbox"/>	Extreme risk for skin breakdown leading to wounds
<input type="checkbox"/>	Spends majority of day asleep or semi-alert, but understands tone of caregiver
<input type="checkbox"/>	Extreme weight loss
<input type="checkbox"/>	Loss of ability to smile – indicates death is near

**Use the Actively Dying Assessment Tool (ADAT) to assess Stage 7 care needs. ADAT is available online at [www.tamcummings.com](http://www.tamcummings.com).**

**Amnesia<sup>1</sup> - the inability to use or retain short-term or long-term memory**

**Aphasia<sup>2</sup> - the inability to use or understand language**

**Agnosia<sup>3</sup> - the inability to use or recognize common objects or people**

**Anosognosia<sup>4</sup> - the inability to recognize impaired function (not denial) in memory, general thinking skills, emotions and body functions**

**Apraxia<sup>5</sup> - the inability to use coordinated and purposeful muscle movement**

**ADLs<sup>6</sup> - Katz's Index of Independence in Activities of Daily Living - bathing, dressing, toileting, transferring, continence and feeding**

**IADLs<sup>7</sup> - Lawton-Brody Instrumental Activities of Daily Living - the ability to use a telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medication**

**Atypical Depression<sup>8</sup> is a form of depression more commonly seen in dementia. Person appears aggressive - either verbally or physically or both, angry, anxious, agitated and/or annoyed.**

**\*Food preparation moves from regular to mechanically chopped to finger foods to pureed. Your doctor will write an order for a speech therapist to evaluate your loved one's ability to chew and swallow food and liquids.**

## Pain Assessment in Advanced Dementia Scale (PAINAD)

**Instructions:** Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

Behavior	0	1	2	Score
Breathing Independent of Vocalization	Normal	<ul style="list-style-type: none"> <li>▪ Occasional labored breathing</li> <li>▪ Short period of hyperventilation</li> </ul>	<ul style="list-style-type: none"> <li>▪ Noisy labored breathing</li> <li>▪ Long period of hyperventilation</li> <li>▪ Cheyne-Stokes respirations</li> </ul>	
Negative Vocalization	None	Occasional moan or groan Low-level speech with a negative or disapproving quality	Repeated troubled calling out Loud moaning or groaning Crying	
Facial expression	Smiling or inexpressive	Sad Frightened Frown	Facial grimacing	
Body language	Relaxed	Tense Distressed pacing Fidgeting	Rigid Fists clenched Knees pulled up Pulling or pushing away Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract, or reassure	
			TOTAL SCORE	

(Warden et al., 2003)

### Scoring:

The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain; 4-6=moderate pain; 7-10=severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

### Source:

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc.* 2003;4(1):9-15.

PAINAD Item Definitions  
(Warden et al., 2003)

Breathing

1	Normal breathing is characterized by effortless, quiet, rhythmic (smooth) respirations.
2	Occasional labored breathing is characterized by episodic bursts of harsh, difficult, or wearing respirations.
3	Short period of hyperventilation is characterized by intervals of rapid, deep breaths lasting a short period of time.
4	Noisy labored breathing is characterized by negative-sounding respirations on inspiration or expiration. They may be loud, gurgling, wheezing. They appear strenuous or wearing.
5	Long period of hyperventilation is characterized by an excessive rate and depth of respirations lasting a considerable time.
6	Cheyne-Stokes respirations are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative Vocalization

1	Smiling or inexpressive. Smiling is characterized by upturned corners of the mouth, brightening of the eyes, and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2	Sad is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3	Frightened is characterized by a look of fear, alarm, or heightened anxiety. Eyes appear wide open.
4	Frown is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5	Facial grimacing is characterized by a distorted, distressed look. The brow is more wrinkled, as is the area around the mouth. Eyes may be squeezed shut.

Body Language

1	Relaxed is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2	Tense is characterized by a strained, apprehensive, or worried appearance. The jaw may be clenched. (Exclude any contractures.)
3	Distressed pacing is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4	Fidgeting is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person
5	Rigid is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding. (Exclude any contractures.)
6	Fists clenched is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7	Knees pulled up is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance. (Exclude any contractures.)
8	Pulling or pushing away is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him- or herself free or shoving you away.
9	Striking out is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability

1	No need to console is characterized by a sense of well-being. The person appears content.
2	Distracted or reassured by voice or touch is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction, with no indication that the person is at all distressed.
3	Unable to console, distract, or reassure is characterized by the inability to soothe the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.

## Actively Dying Assessment Tool (ADAT)

The Final Months	
Significant change in health	Adult Failure to Thrive' diagnosis may be made
Clear and vivid dreams are reported	Withdraw from social/family activities
Talks about missing a loved one	Less interest in food and drink
The Final Weeks	
Less eye contact, more withdrawn	Conversations with people not there
Looking and/or reaching beyond and above	Reports people are telling him/her to "Come on"
Reports seeing/talking to favorite persons	May report strange feelings in limbs
Increased risk of falling	Tires easily
Less interest in food or drink	Voice weakens easily
<i>Don't Be Afraid of Silence</i>	
The Final Days	
May have fever followed by sweats	Pulse and breathing start to slow
Even less interest in food or drink	Kidney and liver function start to slow
General restlessness displayed	Circulation slowing - reposition every 2 hrs
Leg tremors may occur	May begin breathing through the mouth
<i>May Have Sudden Alert Time and Ravenous Hunger</i>	
Have You....	
cried in front of your loved one.	said "I am hurt."
said "I love you."	said "I am lost."
said "I am sad." or "I am angry."	said "I will miss you."
given your loved one permission to go.	talked about death.
The Final Hours	
Fever may come and go	Kidney function very slow, urine becomes dark
Overall calmness, but may pick at covers or PJ's	Mottling - blue/purple color in feet or hands
May not respond to sound or speech	Pressure wounds may open (bed sores)
Eyes may not follow movement around room	Heart rate slows
Exhibits 'doll's eyes'	Respiration slows to < 14 breaths per minute
Trembling/twitching in limbs/sometimes violent	Odor may be present
Gurgling in throat ("Death Rattle")	Apnea begins (stops breathing between breaths)
Bruising from blood clotting system failing	Cheyne-Stokes (Chain-Stokes) breathing
Semi-comatose appearance	Final Breath
Breathing through mouth	May make a "pa" sound or spittle/foam at mouth
Death	
Body appears to shrink almost immediately	Eyes flatten
Body becomes pale, cool and gray	Body may have slight settling movement
Eyes and mouth typically remain open	Body may release urine or stool
Grief After Death, You may...	
feel numb. Be careful driving for several months.	feel agitated and have angry outbursts.
feel physically worse or develop colds.	momentarily forget your loved one is gone.
feel regretful over lost time.	feel forgetful and have trouble concentrating.
feel anger over your loss.	experience a moment of seeing her/him again.
feel physically ill.	have dreams about your loved one.
feel strange sensations in your body.	feel little support. Grieving takes years, not days.

## Caregiver Burden Scale

Rank these statements on how true they are for you as a caregiver, using a scale of 0 to 4 with 0 = Never and 4 = Nearly Always.

- \_\_\_\_\_ I don't have enough time for myself.
- \_\_\_\_\_ I am over-taxed by my responsibilities.
- \_\_\_\_\_ I have lost control over my life.
- \_\_\_\_\_ I am uncertain about what to do for my loved one.
- \_\_\_\_\_ I should do more to help my loved one.
- \_\_\_\_\_ I could do a better job caring for my loved one.
- \_\_\_\_\_ I feel burdened by caring for my loved one.
- \_\_\_\_\_ Total Score

- \_\_\_\_\_ My loved one needs help all of the time.
- \_\_\_\_\_ My loved one depends on me to help her complete her daily tasks.
- \_\_\_\_\_ I fear what may happen to my loved one in the future.
- \_\_\_\_\_ I fear that there will not be enough money to care for my loved one.
- \_\_\_\_\_ I fear I will not be able to continue to care for my loved one.
- \_\_\_\_\_ I wish someone else would take over my caregiving responsibilities.
- \_\_\_\_\_ I feel a sense of strain when I'm with my relative.
- \_\_\_\_\_ Total Score

- \_\_\_\_\_ I sometimes feel anger toward my loved one.
- \_\_\_\_\_ I am sometimes embarrassed by my loved one.
- \_\_\_\_\_ I feel uncomfortable about having friends over.
- \_\_\_\_\_ Caring for my loved one has a negative impact on my relationships with other family and friends.
- \_\_\_\_\_ Caregiving has affected my health.
- \_\_\_\_\_ Being a caregiver impacts my privacy.
- \_\_\_\_\_ Total Score

\_\_\_\_\_ Total points from all scores.

Interpretation: No or Minimal Burden: 0 to 20

Mild or Moderate Burden: 21 to 40

Moderate to Severe Burden: 41 to 60

Severe Burden: 61 to 88

Adapted from The Family Practice Handbook