HHSC: Aging Texas Well Advisory Committee, August 5th, 2020

The Aging Texas Well Advisory Committee advises HHSC and makes recommendations to state leadership on implementation of the Aging Texas Well Initiative.

Texas Gov. Rick Perry issued an executive order creating the Aging Texas Well Advisory Committee and Action Plan. The order, which was issued in April 2005, formalizes the Aging Texas Well Initiative and asks the department to continue its work to identify and discuss aging policy issues, guide state government readiness, and promote increased community preparedness for an aging Texas population.

Under the executive order, an advisory committee is to be formed to advise the Texas Health and Human Services Commission (HHSC) and to make recommendations to state leadership on implementation of the Aging Texas Well Initiative. HHSC creates and disseminates a comprehensive and effective working plan to identify and discuss aging policy issues, guides state government readiness and promotes increased community preparedness for an aging Texas.

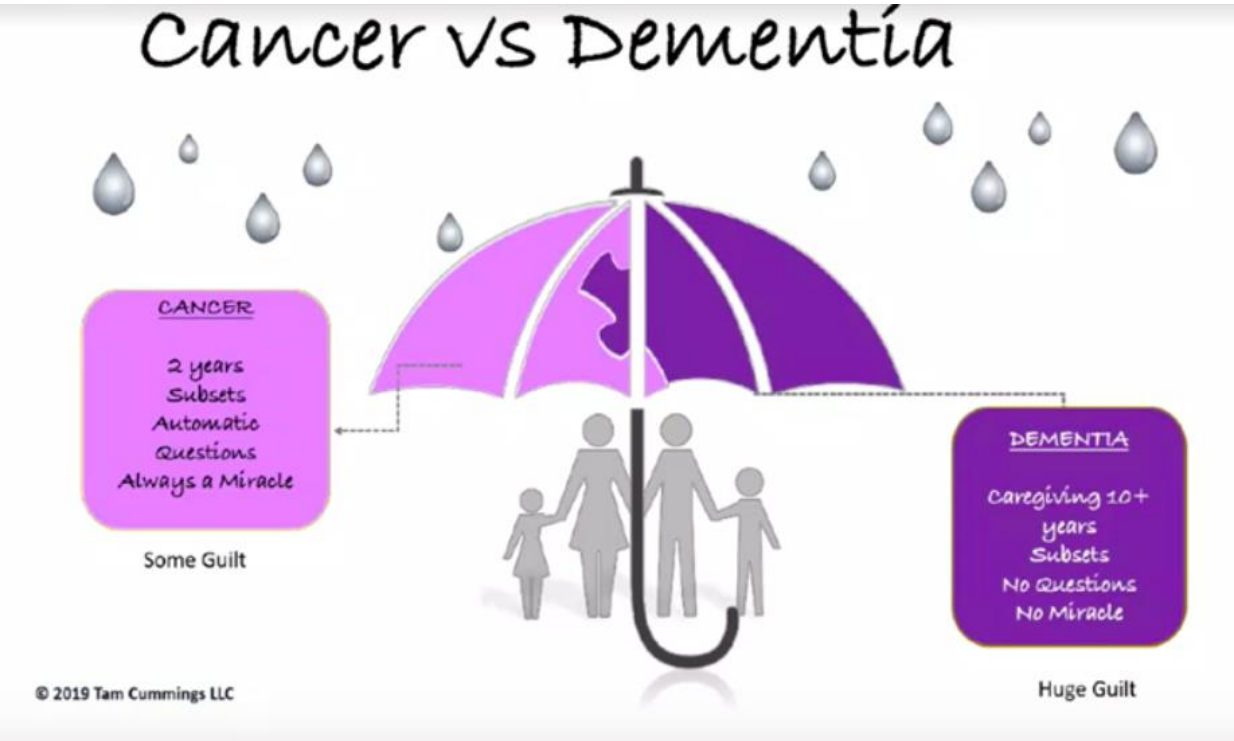
HHSC also leads a planning effort to ensure the readiness of all Texas state agencies to serve an aging population by identifying issues, current initiatives, and future needs.

Dr. Michèle J. Saunders, MD, Chairperson Academic San Antonio **Cindy Adams** Provider/Managed Care Organization Austin **Patricia Bordie** Area Agency on Aging Austin **Bruce Bower** Advocate/Consumer Austin **Andrew Crocker** Academic Amarillo **Richard Flores** Aging & Aging and Disability Resource Center McAllen **Amanda Fredriksen** Advocate/Consumer Austin	**Anna Gray** Advocate/Consumer Austin **Tammy Mermelstein** Faith /Non-profit Organization Houston **Dirk Sheridan** Protections Austin **Tim Spong** Workforce Austin **Lynda Taylor** Physical/Mental Health Austin **Michael Wilson** Older Adult Services Network Austin **Carol Zernial** Faith/Non-profit Organization San Antonio

Welcome, opening remarks, and introductions. The meeting was called to order by Dr. Saunders.

Approve February 5, 2020, meeting minutes. The minutes were approved as drafted.

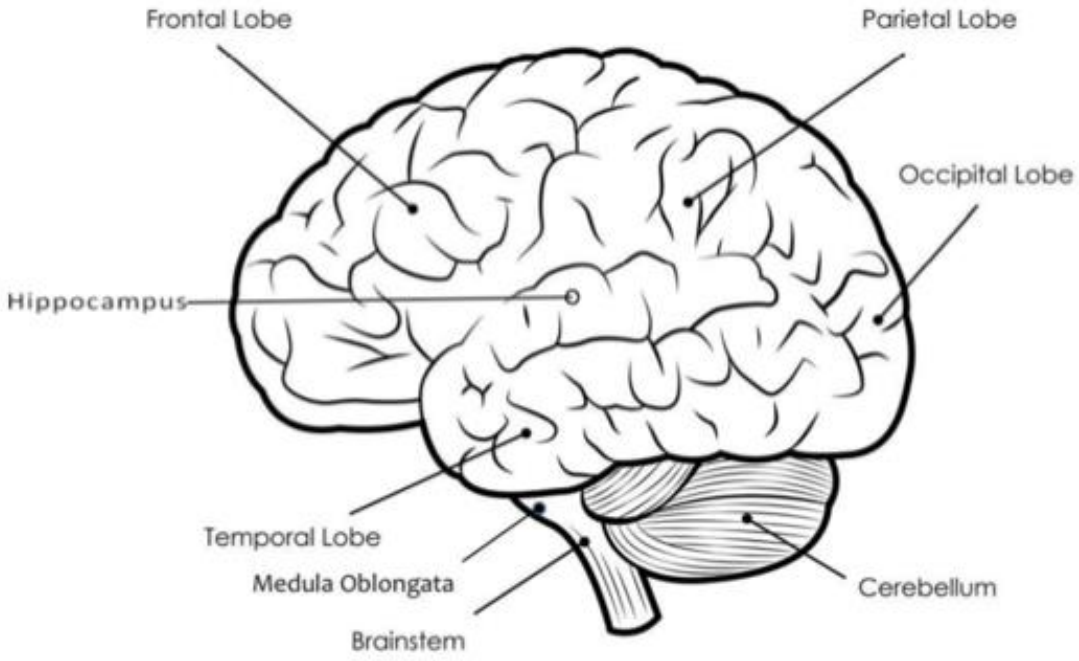
Special Topic: Dementia Aware: Tam Cummings, Ph.D., Gerontologist.



When people are diagnosed with Cancer, they ask all sorts of questions and the dynamic between caregivers is strong. With dementia, that is not the case.

Nine Most Common Dementias

- Mixed Dementia (most people have more than one dementia)
- Alzheimer's
- Vascular Dementia
- Lewy Bodies Dementia
- Frontotemporal Dementia
- Parkinson's Disease Dementia
- Wernicke-Korsakoff Syndrome
- Huntington's Dementia
- Chronic Traumatic Encephalopathy (CTE)



The Hippocampus, Limbic System, and Amygdala are the areas of the brain associated with memory, regulating emotional response, feelings, and reactions. The Hippocampus regulates learning. Its function allows for a person to have a cognitive map or a blueprint of where the Hippocampus has coded memory, then store specific memory into certain areas of the brain's lobes. When it functions, a person can recall of memory correctly. The Hippocampus also moves short-term memory to long-term memory, encodes and consolidates memory and is responsible for spatial navigation and spatial memory. In other words, it allows you to make memory, decides where to store the memory and how that memory connects to other events, and holds the map of where memory is in the brain.

Signs of Impairment:

- Inability to learn new information, such as a new grandchild's name.
- Repetitive questioning, "When is my doctor's appointment?" "Why haven't you fed me?"
- Then later "Who are you?" "Who am I?"
- Connections to all forms of memory are lost.

The Amygdala is also involved in moving events to memory, making decisions, and regulating your emotional response to the world around you.

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The Limbic System monitors lower order emotional processing input from the sensory systems. Motivation, memory, learning, and emotion are all functions of the Limbic Systems. It influences the endocrine system and the autonomic nervous system and has a role is sexual arousal.

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.

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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

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- 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

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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

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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.		

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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.

A.	Ability to Use Telephone		
	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.	Shopping		
	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
C.	Food Preparation		
	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
D.	Housekeeping		
	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
E.	Laundry		
	1.	Does personal laundry completely.	1
	2.	Launders small items; rinses socks, stockings, etc.	1
	3.	All laundry must be done by others.	0
F.	Mode of Transportation		
	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
G.	Responsibility for own Medication		
	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
E.	Ability to Handle Finances		
	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
		Score:	_____

GERIATRIC DEPRESSION SCALE (GDS, SHORT FORM)

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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?	**yes**/no	
3.	Do you feel that your life is empty?	**yes**/no	
4.	Do you often get bored?	**yes**/no	
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?	**yes**/no	
7.	Do you feel happy most of the time?	yes/**no**	
8.	Do you often feel helpless?	**yes**/no	
9.	Do you prefer to stay at home, rather than going out and doing new things?	**yes**/no	
10.	Do you feel you have more problems with memory than most?	**yes**/no	
11.	Do you think it is wonderful to be alive now?	yes/**no**	
12.	Do you feel pretty worthless the way you are now?	**yes**/no	
13.	Do you feel full of energy?	yes/**no**	
14.	Do you feel that your situation is hopeless?	**yes**/no	
15.	Do you think that most people are better off than you are?	**yes**/no	
		Score:	

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

DEMENTIA BEHAVIORAL ASSESSMENT TOOL

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STAGE 1 or NORMAL AGING	
	BEHAVIOR CHARACTERISTICS
☐	No cognitive changes evident. Normal aging, normal brain function.
STAGE 2 or EARLY STAGE or MILD COGNITIVE IMPAIRMENT (MCI)	
	BEHAVIOR CHARACTERISTICS
☐	Fleeting moments of cognitive loss
☐	Recovers relatively quickly from mistakes, may correct self
☐	Misplaces familiar objects
☐	Forgets names he/she knows well
☐	No problems completing tasks or at social functions
☐	Exhibits appropriate concern over memory function
☐	Vacillates between seeking medical care and ignoring symptoms
☐	Functions effectively at work and at home
☐	Highly functional social skills
☐	Requires complete cognitive testing to determine illness
☐	Responds to cognitive therapy
☐	Scores well on orientation test
☐	Amnesia[1] beginning to be expressed
☐	May become defensive when questioned
☐	Easily irritable
☐	Easily frustrated by common tasks
STAGE 3 or MIDDLE STAGE or BEGINNING DEMENTIA	
Minimal brain tissue lost	**Stage thought to last 1-4 years**
Abilities equivalent of 12 years old to adulthood	
	BEHAVIOR CHARACTERISTICS
☐	Memory deficit evident in intensive interview
☐	Attempts to conceal deficits and denies any cognition difficulties
☐	Expresses concern regarding deficits (mild/moderate anxiety)
☐	Problems performing in demanding situations (work or social)
☐	Co-workers/family members beginning to be aware of increasing challenges
☐	Can get lost traveling to new areas
☐	Exhibits signs of cognition but may retain little new information
☐	Name/Word finding difficulty more frequent
☐	Challenged to remember new names
☐	May appear depressed
☐	Demonstrates high social skill level
☐	Uses humor to avoid answering questions
☐	No noticeable physical changes, but may begin stumbling or falling or sleeping excessively
☐	Beginning to skip steps in tasks

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☐	Able to score well on orientation test, but not on cognition exam	
☐	At times appears befuddled or confused	
☐	Amnesia[1] and Aphasia[2] present - needs new information repeated	
☐	Increased episodes of sudden irritability	
☐	Quickly agitated and defensive of memory	
☐	Sundowning may begin	
LBD	Accuses caregiver of theft	
	Accuses caregiver of infidelity	
	Rapid onset of dementia	
	Loss of facial affect	
STAGE 4 or MIDDLE STAGE or MODERATE DEMENTIA		
Stage thought to last 1-4 years		**4 ounces brain tissue loss**
Abilities equivalent of 12 years old to adulthood		
	BEHAVIOR CHARACTERISTICS	
☐	Decreased knowledge of current and recent events	
☐	Memory deficits regarding personal history, may look to spouse to answer questions	
☐	Decreased ability to perform serial subtractions (100-7, 93-7, 86-7, etc)	
☐	Difficulty with immediate recall - for example, what time is doctor's appointment?	
☐	Difficulty with complex tasks such as driving, finances, shopping, bathing	
☐	Denial of deficits, with or without agitation and annoyance	
☐	Withdraws from challenging situations - refuses to complete tasks, may make excuses	
☐	Increased anxiety/frustration abilities or loss of abilities	
☐	Difficulty telling jokes, stories - starting to mix up stories	
☐	Decreased facial affect (emotion on face)	
☐	Increased depressive symptoms, possibly Atypical[8].: anxiety, anger, agitation, aggression	
☐	May hesitate when trying to correctly identify family members or close friends	
☐	Can have normal cognition for hours or days, then become quite confused	
☐	May become lost in tasks	
☐	Greater language challenges, word-finding difficulty	
☐	Begins to have stumbles or falls	
☐	Begins to shadow caregiver	
☐	Begins to have difficulty with ADLs[6] or IADLs[7]	
☐	May begin keeping lists of family names, phone numbers, etc.	
☐	Exhibits greater desire for sweet foods	
☐	May score well on orientation test, dementia evident on cognition exam	
☐	Amnesia[1], Aphasia[2], Agnosia[3], and Anosognosia[4] present, some paranoia present	
Nursing:	Coordination beginning to be impaired	
EARLY STAGE 5 or LATE STAGE or MODERATELY SEVERE DEMENTIA		
Stage thought to last 1-3 years		**1/2 to 1 pound of brain tissue loss**
Abilities equivalent of 12 - 8 year old		
	BEHAVIOR CHARACTERISTICS	
☐	Disorientation to time (date, day of week, season, etc.) or place	

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☐	Immediate memory relatively intact - knows self and family
☐	May need assistance choosing and layering clothing, but denies need for IADL/ADL
☐	May crave sweets over other foods
☐	Begins to have falls
☐	Hunting and gathering stage, waders from room to room collecting items
☐	Urinary incontinence begins - monthly to weekly to daily
☐	Wears clothing appropriately (hearing aid, glasses, carries purse)
☐	*Feeds self (may need meal set-up)
☐	Sleep disturbances, excessive sleeping or napping
☐	Can score well on an orientation test, but not a cognition test
☐	Wanders looking for a way out (purposeful wandering/Sundowning)
☐	Follows simple instructions for ADLs, verbal cues needed for tasks
☐	Unexplained tearfulness or extreme laughter
☐	Catastrophic reactions - may be easily annoyed, agitated, verbally or physically aggressive
☐	Hallucinations, accusatory behavior, excessive sleeping - report to doctor
☐	Amnesia[1], Aphasia[2], Agnosia[3], and Anosognosia[4], and Apraxia[5] evident to outsiders
☐	May make comments about death
Nursing:	Vital signs should be stable
	Begin recording monthly body temperature and weight
	Begin PAINAD monitoring
LATE STAGE 5 or LATE STAGE or MODERATELY SEVERE DEMENTIA	
Abilities equivalent of 8 - 4 year old	
☑	**BEHAVIOR CHARACTERISTICS**
☐	May begin having chronic Urinary Tract Infections (UTIs)
☐	Appears severely depressed with increased loss of facial affect
☐	Increased fall risks, may not recognize severity of the fall especially to the head
☐	Coordinated movement/function beginning to be affected
LATE STAGE 5 or LATE STAGE or MODERATELY SEVERE DEMENTIA continued	
☐	Begins to be lost in current time
☐	Difficulty recognizing self in a mirror
☐	Challenged to recall family members, may confuse daughter with mother, etc
☐	Accuses family members, caregivers of theft, infidelity, lying, increased paranoia possible
☐	Automatic "yes/no" speech functions, but without understanding
☐	May begin using curse words as temporal lobes become damaged
☐	Changes in visual perception increasing, bumps into objects, peripheral vision damaged
☐	Difficulty interpreting background noise
☐	Challenged to perform rehab for injuries, may appear stubborn to therapist/family
☐	Cannot give accurate information, verbal skills damaged
☐	Caregivers may confuse behavior for purposeful active - lying, etc.
☐	Physical Appearance beginning to be affected
☐	Pilling or rubbing hand motions common, may enjoy folding items

Nursing:	Hyperoral behavior may begin
	UTIs require culture and sensitivity (C&S) orders
	Continue monthly body, temperature, and weight checks
	Sleep disturbance beginning
STAGE 6 or LATE STAGE or SEVERE DEMENTIA	
Stage thought to last 1-3 years	**1 to 1 1/2 pounds of brain tissue loss**
Abilities equivalent of 4 - 2 year old	
	BEHAVIOR CHARACTERISTICS
☐	Unable to recall most recent events
☐	Repetitiveness in motion or speech or memory
☐	May be in constant motion, wanders/walks for hours
☐	Removes/won't wear clothing appropriately
☐	Disregards eyeglasses, dentures, hearing aids (Agnosia[3]) - may throw them away
☐	Refuses to change clothing, unable to complete IADLs and a few ADLs
☐	*Feeds self with set-up, cues and assistance
☐	Bowel incontinence begins
☐	Sleep disturbances - may increase sleep, may require little sleep
☐	Catastrophic reactions may occur - great resistance to care giving, bathing
☐	Purposeless wandering/Sun-downing (wandering without an agenda)
☐	Cannot complete a two-stage command, such as pick up a piece of paper and fold it
☐	Apraxia[5] advanced, gait altered (small shuffling steps)
☐	Weight loss beginning, may lose 1/3 or more of body weight
☐	Difficult to engage with caregiver, challenged to initiate conversation
☐	Disheveled appearance
☐	Fall risk continues to increase until wheelchair bound, risk for fractured bones increases
☐	Difficult to perform rehab for injuries
☐	Almost total loss of facial affect
☐	May suddenly use complete sentence, then only words or sounds
☐	Ability to taste sweets drives appetite
Extensive brain tissue loss and/or damage	
Nurses Careplan:	Weight loss of 1/3 to 1/2 body weight
	Add high calorie snacks and finger foods
	Spiral fracture of hip (6x more likely to break bones)
	Full set vitals and weight monthly
	Occipital blindness - left eye doesn't function
	Speech Therapist evaluation ordered when pocketing, choking, swallowing issues noted with food or liquid
	Falls now directly linked to pre-motor cortex damage
	Hyperoral
	Routine performance of Braden Scale for Predicting Pressure Sore Risk
	Monthly PAINAD review - pulse increases with pain

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Nurses Careplan:	Monitor clothing for warmth as body temperature drops
	Monitor clothing for warmth as body temperature drops
STAGE 7 or LATE STAGE or VERY SEVERE DEMENTIA	
Stage thought to last 1-2 years	**1 1/2 - 2 pounds of brain tissue loss**
Abilities equivalent of 2 year old to infant	
	BEHAVIOR CHARACTERISTICS
☐	Frequently no speech at all - mostly grunting or word sounds
☐	*Cannot feed self --- chipmunking or holding food in cheeks, high risk for choking
☐	Unable to sit up independently, unable to hold head up
☐	Loss of basic psychomotor skills (unable to walk w/o assistance)
☐	Hyperoral (may put everything in mouth)
☐	Displays great muscular flexation, hands curl, arms and legs pull up
☐	Extreme risk for skin breakdown leading to wounds (Braden Scale*)
☐	Spends majority of day asleep or semi-alert, but understands tone of caregiver
☐	Extreme weight loss
☐	Loss of ability to smile -- indicates death is near
☐	Total care required
Nursing	PAINAD review monthly
	Braden Scale - weekly then daily as skin integrity is threatened
	Braden Scale - weekly then daily as skin integrity is threatened
ACTIVELY DYING ASSESSMENT TOOL (ADAT)	
The Final Months	
	Significant change in health
	Clear and vivid dreams are reported
	Talks about missing a loved one
	Adult Failure to Thrive diagnosis may be made
	Withdraw from social/family activities
	Withdraw from social/family activities
The Final Weeks - Skin breakdown risk increases. Especially buttocks, hips, and heels.	
	Less eye contact, more withdrawn
	Looking and/or reaching beyond and above
	Reports seeing/talking to favorite persons
	Increased risk of falling
	Less interest in food or drink
	Conversations with people not there
	Reports people are telling him/her to "Come on"
	May report strange feelings in limbs
	Tires easily
	Voice Weakens easily
	Voice Weakens easily
The Final Days	
	May have fever followed by sweats

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	Even less interest in food or drink
	General restlessness displayed
	Leg tremors may occur
	Pulse and breathing start to slow
	Kidney and liver function start to slow
	Circulation slowing - reposition every 2 hours
	May begin breathing through mouth
	May begin breathing through mouth
	May Have Sudden Alert Time and Ravenous Hunger
	The Final Hours
	Fear may come and go
	Overall calmness, but may pick at covers or PJ's
	May not respond to sound or speech
	Eyes may not follow movement around room
	Exhibits "doll's eyes"
	Trembling/twitching in limbs/sometimes violent
	Gurgling in throat ("Death Rattle")
	Bruising from blood clotting system failing
	Semi-comatose appearance
	Breathing through mouth
	Kidney function very slow, urine becomes dark
	Mottling - blue/purple color in feet or hands
	Pressure wounds may open (bed sores) in hours
	Heart rate slows
	Respiration slows to <14 breaths per minute
	Odor may be present
	Apnea begins (stops breathing between breaths)
	Cheyne-Stokes (Chain-Stokes) breathing
	Final Breath
	May make a "pa" sound or spittle/foam at mouth
	May make a "pa" sound or spittle/foam at mouth
	Death
	Body appears to shrink almost immediately
	Body becomes pale, cool, and gray
	Eyes and mouth typically remain open
	Eyes flatten
	Body may have slight settling movement
	Body may release urine or stool

Amnesia[1] - the inability to use or retain short-term or long-term memory

Aphasia[2] - the inability to use or understand language

Agnosia[3] - the inability to use or recognize common objects or people

Anosognosia4 - the inability to recognize impaired function (not denial) in memory, general thinking skills, emotions and body functions

Apraxia[5] - the inability to use coordinated and purposeful muscle movement

ADLs[6] - Katz's Index of Independence in Activities of Daily Living - bathing, dressing, toileting, transferring, continence and feeding

IADLs[7] - 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[8] - is a form of depression more commonly seen in dementia. Person appear aggressive - either verbally or physically or both, angry, anxious, agitated and/or annoyed

Braden Scale for Predicting Pressure Sore Risk* - developed to foster early identification of patients at risk for forming pressure sores. The scale is composed of six subscales that reflect sensory perception, skin moisture, activity, mobility, friction and shear, and nutritional status

*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 foods 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	• Occasional labored breathing • Short period of hyperventilation	• Noisy labored breathing • Long period of hyperventilation • Cheyne-Stokes respirations	
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: 13=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.

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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.

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 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 on 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.
_____ Being a caregiver impacts my privacy.
_____ Total Score

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

Questions/Answers/Comments
One of the big issues in terms of pain in early dementia is oral health. There may be no clues that the pain is happening unless there are indicative facial expressions and body language. Dental issues should always be checked. It is an infection area that is right next to the brain cavity.

Caregivers experiencing burnout is an important issue and the tools presented here will be very helpful.

Nurses have found myriad ways to manage. For example, with Alzheimer's patients who are wanderers, they have found that it is very helpful to disguise doors and doorknobs as something else so that patients don't experience a reflex to open the door and end up wandering about. The speaker stated that that makes a great deal of sense, but is actually illegal in some states. Before we had alarm system, we would place a three-foot black rug on the ground in front of doors, because to a person with advanced dementia, that looks like a hole in the ground and they would be less likely to cross it. We've also tried painting stop signs on doors and placing latches at the top of doors because we're never trained to open a door from the top. The ideal situation is memory care communities where people can go in and out of doors and into yard areas. However, that's not the case for some communities.

We should be engaging the larger community with the effort to get this information out to people and not just the state websites.

There was discussion about the different ways that public engagement can occur regarding dementia, including public information and education.

Committee Operations: Members provide updates from their respective organizations. Some members did not identify their organization and so their contribution was not noted.

Triple As. Food/food insecurity and rental assistance are significant issues in the context of COVID-19. They received additional federal funding through the CARES Act. The Ombudsmen were told to stay out of the nursing facilities, and they are having to work over the phone. Health and wellness classes are continuing.

Texas Senior Advocates Coalition. They are developing priorities for the legislative session and working on Senior Day at the Capitol. They are concerned about how the legislature and the committees will be meeting (virtually or live).

Texas A&M AgriLife Extension. A digital education strategy will be finding its way into our educational process. The AgriLife extension agents are playing a role in helping HHSC and DSHS with contact tracing.

Aging and Disability Resource Center. A good informational resource for consumers and patients.

APS. With COVID-19 spreading, their clients have been isolated and unable to socialize with others. They are concerned about the caseload, even though it has gone down. However, we have seen an increase in the last month in some of the Metropolitan areas and in South Texas.

HHSC stated that the plan for Alzheimer's Disease has been completed and the Alzheimer's Council will be holding a virtual meeting August 12th. A public service announcement has been prepared.

Meals on Wheels. They have moved away from daily delivery to two-week meal delivery intervals. Meals are still occurring to congregate participants as well. The home repair programs and online bingo have been continued. We are supporting clients from a distance.

The Chair stated that the Health Science Center has seen their ERs are still full and all ventilators are occupied.

Public Comment. No public comment was offered.

Action/agenda items for next meeting and wrap-up:

- November 4th is the next meeting
- Critical social engagement activities will be gathered
- The next meeting will include division updates and will be virtual

Adjourn. There being no further business, the meeting was adjourned.

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