

DYSPHAGIA IN THE EARLY STAGES OF DEMENTIA

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Dementia Defined

- The American Psychiatric Association defines dementia as:
 - A deterioration of intellectual capacities that has a significant negative impact on social and personal functioning.
- A group of symptoms that may accompany certain diseases of physical conditions, but not a disease in and of itself.



Dementia Defined (cont'd)

- Dementia is a deterioration in intellectual capacity with impairments in at least 3 of the following spheres of mental activity:
 - Language
 - Visuospatial Skills
 - Cognition
 - Memory
 - Personality

Types of Dementia

- Alzheimer's Disease
 - Most common form of dementia.
 - Caused by a loss of brain cells.
 - Not reversible; not curable.
 - Disease process can be slowed.
 - Definitive diagnosis via autopsy.



Types of Dementia (cont'd)

- Vascular dementias, including multi-infarct dementia:
 - Second most common form of dementia.
 - Caused by poor circulation of blood to the brain, often by repeated TIAs.
 - Progression can be slowed by controlling hypertension, diabetes, and overall vascular health.

Types of Dementia (cont'd)

- Lewy body dementia:
 - Caused by abnormal deposits of protein in nerve cells.
 - Symptoms often mimic Parkinson's Disease.
 - Thinking, attention, and concentration more impacted than memory and language.
 - Not reversible; not curable.
 - Same medicines used to slow Alzheimer's also have been shown to be effective here.

Types of Dementia (cont'd)

- Other
 - Alcohol-related dementia.
 - Pick's Disease (frontotemporal dementia).
 - Senile dementia.
 - AIDS-related dementia.

Cognitive Disability

- With most dementias, progression of disease and/or predictable patterns of cognitive loss can be identified.
- Cognitive disability requires making adjustments in daily activities and life roles.
- Functional assessment helps to clarify the adjustments needed and the level of care that must be provided.

STAGING DEMENTIA:

- Helps facilitate the documentation of the level of dementia that correlates to predictable characteristics of cognition, communication, mood, behavior and ADL ability.
- Provides a common language for all clinicians to use in the caring of the person.
- Assists in tracking of the disease progression.

Staging Dementia (cont'd)

- Multiple tools exist (e.g., Global Deterioration Scale, Allen Cognitive Levels).
- Staging tools help provide a description of functional capabilities .
- Global Deterioration Scale (GDS) most common interdisciplinary tool:
 - Breaks dementia into 7 stages that describe the degenerative process over 8 to 10 years.

Global Deterioration Scale (GDS)

- Stage 1
 - No cognitive decline
- Stage 2
 - Very mild cognitive decline
- Stage 3
 - Mild cognitive decline
- Stage 4
 - Moderate cognitive decline

GDS (cont'd)

- Stage 5
 - Moderately severe cognitive decline
- Stage 6
 - Severe cognitive decline
- Stage 7
 - Very severe cognitive decline

Anticipation vs. Reality

- Therapists are in a unique clinical situation, in that we need to anticipate the changes associated with advancing dementia while at the same time meet the patient's needs in the reality of the present.



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Anticipation vs. Reality

- We can anticipate certain types of clinical cascades by becoming keen observers/evaluators in the present.
- There are clinical strategies/adaptations that are best introduced prior to the patient's actual need.
- Improves retention of functional use of such strategies/adaptations.

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Perception vs. Reality

- "Perception is reality."
- Anticipation is not the same as perception. Though we can clinically anticipate certain needs, it is important that we don't perceive the patient as being less able than what they actually are in the present.

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DYSPHAGIA AND DEMENTIA: THE SCOPE OF THE PROBLEM

- Individuals with Alzheimer's Disease weigh less than those with multi-infarct dementia and less than non-demented controls (Singh, 1988).
- Over half the residents in nursing homes are totally dependent in feeding (Siebens, et al, 1986).
- The cost of managing eating dependency accounts for 25% of the total cost of care in nursing homes

- The severity of dementia will increase the chances of aspiration pneumonia (Wada, et al, 2001).
- Individuals with dementia are more at risk for dehydration due to inability to seek liquids, diminished thirst, a decrease in body mass (reducing water content of body), and decline in the ability to filtrated water due to renal failure (Garcia, 2001).

- Poor oral care is not uncommon in the elderly and contributes not only to swallowing deficits but to weight loss, eating problems, dehydration, and behavioral problems.
- The ratio of hydration for thin versus nectar is 3 to 4 (4 ounces of thin equals 3 ounces of nectar)
- Thickening liquids adds approximately \$.01 to the cost of every ounce of liquids

- 30% of all PEG tubes inserted in the US will be in individuals with dementia (Cervo, et al, 2006)
- As many as 10% of the total population in nursing homes in the US are being fed by PEG tubes (Cervo, et al, 2006)

WHY DO INDIVIDUALS WITH DEMENTIA HAVE DIFFICULTY EATING/SWALLOWING?

- Memory difficulties result in the individual thinking they have just eaten so they do not have the sensation of hunger.
- Perceptual, spatial difficulties and motor impairment result in deficits in handling utensils and food.
- Language difficulties will decrease ability to express food preferences and/or problems with understanding mealtime instructions.

- Difficulty in sitting for a meal.
- Difficulty in recognizing food.
- Problems in understanding mealtime instructions.
- Socially inappropriate mealtime behavior.

WHAT WE KNOW ABOUT SWALLOWING AND SPECIFIC TYPES OF DEMENTIA

ALZHEIMER'S DISEASE:

- Reduced lingual peristalsis resulting in diffuse bolus formation and delayed bolus transit.
- Difficulty with mouth opening.
- Muscle spasms including oral musculature.
- Delayed initiation of the swallow reflex.

VASCULAR (MULTI-IMFARCT) DEMENTIA

- Hemiparesis including oral musculature resulting in poor labial seal and reduced bolus control.
- Reduced ability for hand to mouth activities.
- Variety of deficits based on the areas of infarction.

LEWY BODY DEMENTIA:

- Deficits with attention to meal may lead to a lack of desire to eat.
- Visual-spatial deficits making self feeding difficult.
- Recurrent hallucinations may lead to refusal for assistance in feeding.
- Parkinson's motor features.

PICK'S DISEASE:

- Loss social skills for eating.
- Consumption of food is done quickly with cramming food increasing risks of aspiration.
- Development of a liking to sweet foods.

THE EVALUATION: SOME CONSIDERATIONS

- Read the chart thoroughly noting diet level and restrictions (NAS, cardiac, etc).
- Review weight record and when available average consumption for each meal.
- Look at typical positioning at meals and location that most meals are consumed.

- Talk to the caregivers about behavioral issues they have with the individual at meals.
- Trial different levels of food/liquids without any facilitation techniques or strategies
- Consider doing the evaluation in multiple parts as well as observing the individual feed themselves or be fed

DIAGNOSIS OF DYSPHAGIA

- No Impairment: the individual is able to safely swallow all consistencies of liquids and solids without delay and without any signs of difficulty
- Mild Impairment: the individual has difficulty chewing the hardest consistency, slight increase in lingual peristalsis or slight delay in onset of the swallow reflex

- Moderate Impairment: difficulty in chewing several consistencies, bolus control with liquids, coughing noted resulting in the individual reducing their consumption
- Severe Impairment: very little bolus formation and management, significant delay in onset of the swallow resulting in significant reduction in their ability to consume food sufficient for their nutritional needs

- Profound Impairment: unaware of the need to eat or that food is present, symptoms of aspiration noted at each meal resulting in significant risk for malnutrition/dehydration and/or pneumonia

DETERMINING NEED FOR FURTHER DIAGNOSTIC PROCEDURES

- There is suspicion that pharyngeal stasis is occurring resulting in fever, reduced respiratory function, or other potentially life-threatening issues
- There is questionable esophageal symptoms that negatively impacting the individuals ability to safely consume food

- The symptoms of dysphagia are so diffuse that objective data is necessary to determine the presence and type of dysphagia and to make recommendations for diet level and the need for intervention

TYPES OF DYSPHAGIA

- Oral Stage Dysphagia
- Pharyngeal Stage Dysphagia
- Esophageal Dysphagia
- Mixed Dysphagia

ORAL STAGE DYSPHAGIA

- Labial leaking resulting in anterior leakage reducing nutritional intake
- Reduced lingual peristalsis limiting the ability to form and manipulate the bolus posterior
- Pocketing or storage of food potentially providing debris that can trickle into the airway resulting in aspiration

PHARYGEAL STAGE DYSPHAGIA

- Delayed onset of the swallow reflex resulting in an open airway as the bolus is propelled posterior into the pharyngeal area
- Stasis in the area of the valleculae that could result in aspiration
- Reduced closure of the airway causing solid food or liquid particles to travel into the lungs

ESOPHAGEAL DYSPHAGIA

- Reduced esophageal peristalsis resulting in food falling too slowly causing food or liquids to travel superiorly potential traveling into the airway
- Esophageal reflux where food is either at the inferior end of the esophagus or the stomach and is returned into the superior end of the esophagus

MIXED DYSPHAGIA

- A combination of symptoms (oral, pharyngeal, and/or esophageal)

DIET LEVEL CONSIDERATIONS

- Provide a diet level that is safe
- Provide a diet level that can be effectively AND efficiently provided by caretakers
- Provide a diet that will support the need for nutrition and hydration

- There is minimal concern that the individual can safely hold a cup, glass, or utensil without injury or excessive spillage unless you are certain they will have assistance with all liquids including water at bedside

LIQUID LEVELS

- Thin
- Nectar
- Honey
- Pudding

THIN LIQUIDS

- There is no concern that the individual can consume the consistency with any type of liquid (water, juice, coffee, milk, etc)
- There is adequate labial seal
- There is little or no evidence of oral retention
- There is no evidence of pharyngeal symptoms (coughing, wet vocal quality, etc)

NECTAR LIQUIDS

- There is at least mild reduction in labial sealing causing anterior spillage
- There is a reduction in bolus transit whereby the slight increase in consistency will compensate for the deficit
- There is at least fair residue after the swallow with thin level liquids
- There is more than occasional pharyngeal symptoms with thin liquids

HONEY LIQUIDS

- There is significant anterior spillage to the extent that the majority of the liquids spills out of the oral cavity
- There is reduced lingual peristalsis so that the individual is unable to propel the bolus posterior or compensate for the deficit
- There is more than occasional difficulty with thin or nectar level liquids

PUDDING LIQUIDS

- There is such labial leakage that any other level of liquid would result in almost no liquids remaining in the oral cavity to be swallowing
- There is limited lingual movement to facilitate bolus control and posterior bolus propulsion

DYSPHAGIA LEVEL 5 (REGULAR)

- The level of food is safe whether the individual is able to self-feed or be fed by a caretaker.
- There is little or no concern that the individual can consume any food presented with little or no alteration.
- The individual is able to be consume adequate calories to meet their nutritional needs.

EXAMPLES:

- Whole chicken breast, pork chop, sausage, or steak
- Steak fries
- Hamburger or hot dog on a bun
- Whole fruits

DYSPHAGIA LEVEL 4 (MECHANICAL SOFT)

- The individual has decreased ability to cut food into segments small enough to be safely ingested.
- The individual has decreased mastication skills or rate/bolus size decrease safety.
- The individual has mild to moderate residue of solid food after the swallow.
- The individual is unable to be positioned so that regular consistency is viewed as safe.

EXAMPLES:

- Chopped meat or poultry
- Chopped meatballs
- Chopped vegetables
- Cereal
- Soft breads

DYSPHAGIA LEVEL 3 (CHOPPED)

- Mastication skills are decreased or rate/bolus size significantly interfere with safety.
- Limited ability to form cohesive bolus and propel posteriorly.
- Poor/limited dentition

EXAMPLES:

- Ground meatballs
- Ground French toast
- Ground noodles
- Ground vegetables

DYSPHAGIA LEVEL 2 (MINCED)

- Limited mastication skills .
- Rate of intake and/or bolus size is such that significant risk with more difficult consistencies.
- Poor rotary jaw movement limits ability to form solid bolus and propel with excessive debris.

EXAMPLES:

- Minced meat (Chopped finely).
- Flaky/soft fish without crust
- Minced vegetables.
- Pureed vegetable soup.

DYSPHAGIA LEVEL 1 (PUREED)

- The individual has little or no labial seal so that the majority of a higher level consistency would not be ingested.
- There is severe decrease in mastication skills so that the individual is unable to form a bolus or propel it timely posterior.
- There are signs/symptoms of pharyngeal stasis.

EXAMPLES:

- Pureed meats/fish
- Scrambled eggs.
- Pureed breads.
- Pureed vegetables.

TO TREAT OR NOT TO TREAT

- There is the presence of dysphagia symptoms with their current diet.
- There is a concern that the individual's ability to consume food will not meet their nutritional needs unless the food/liquid is altered.
- Caregivers need education to safely present the food to the individual or provide the food to individuals who must be fed.

- There has been a change in their condition or medication that warrants intervention.
- The individual's typical position for meals places them at risk for dysphagia.
- The individual is responsive to commands (if they self feed) or allow you to feed them.

TREATMENT CONSIDERATIONS

- Food intake is a social activity and should remain as such until it is not feasible or in the best interest of the patient you are treating or other individuals.
- All treatment should focus on the rebuilding of normal neural pathways and as such a diet downgrade at the beginning of treatment may be indicated.

- Treatment should be a tactile experience; as such, you do not necessarily have to clean food debris outside the oral cavity unless the dignity of the patient is compromised or for reasons of safety.
- Treatment should include a meal in bed and a meal while seated.
- Part of your treatment will deal with behaviors.

- Effective treatment may need to occur at a variety of times or with sessions that are split into smaller sections of time.
- Treatment may include meals as well as snacks.
- Treatment ALWAYS should include education specific to the patient AND to general good - feeding techniques.

- Determine where it is best that both you and the patient sit during treatment.
- Chewing and swallowing sounds will facilitate the multi-sensory approach to the meal.
- Conversations about food enhance the therapeutic process and the multi-sensory approach to therapy.

- It is easier to dehydrate than to starve so ALWAYS have liquids as a part of your treatment and end every treatment with liquids.

Keep in mind.....

- New learning is also now a significant challenge.
- How will this knowledge impact my selection of strategies/interventions in working with individuals with dysphagia?

Postural Considerations

- Conceptually, stability before mobility.
- Applies to functional tasks such as eating/feeding as well.
- What do we observe in the present and what can we clinically anticipate?


Postural Considerations

- Supported in correct anatomical position:
 - midline/neutral.
 - facilitation of required movements without negative consequences (e.g., friction/shear).



Postural Considerations

- Patients should not have to utilize compensatory strategies in order to obtain stability. We should be building the stability in for them.



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Postural Considerations

- Neck hyper-extension/hyper-flexion.
- Presence of tone/rigidity.
- Potential for/presence of contractures.
- All postural concerns require an interdisciplinary approach to obtain the best configuration/interventions for the patient.

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AUDITORY PROCESSING AND DEMENTIA:


- Auditory processing time slows.
- As such, consider the environmental noise and need for increased time to comprehend and follow directions.
- Ask yourself: Is the area too noisy or too quiet? Will the area calm the patient? Will the area validate and encourage the patient to eat?

Auditory Processing

- Consider our treatment approach
 - How many words?
 - How many cues?
 - Voice tone..
 - Volume.
- What is our response when a patient doesn't respond?

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Vision/visual processing



- Decreased peripheral vision
- Decreased visual acuity?
- Changes in visual field
 - downward gaze
 - narrowing of visual field

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Adaptations & Strategies

- Education of caregivers, staff, and family.
- Begin routinization early.
- Introduce adaptations early.
- Be consistent.
- Don't expect independent carry-over.

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Adaptations & Strategies (cont'd)

- Be able to meet the patient in their world, in their reality. (Validation theory).
- Slow down.
- Be direct.
- Be patient.

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Postural adaptations/strategies

- Involve PT/OT
 - cushions
 - lateral supports
 - height of foot plates/arm rests
 - width of chair
 - patient's ability to self-propel/reposition self
 - facilitation/inhibitory techniques
- Everything within reasonable reach/accessible
- sitting in dining room chair for meals
- walk to dine programs

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Auditory adaptations/strategies:

- hearing aids/amplification devices.
- go second rule.....
- speak directly to the patient, at their level within their visual field as well.
- limit the level and type of background 'noise.'

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Visual adaptations/strategies

- Remove bi-focals if patient is always gazing downward (Lanny Butler -iatbdementiacare).
- Place setting should be distinct & consistent.
- Contrast colors .
- Food items/drink should be directly in front of patient.
- Re-plate food .
- Use cue cards.

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Additional strategies....

- As we gather more historical information about the patient, we may develop individualized options related to feeding strategies.
- These strategies might include the way food is prepared, packaged, presented, or the sequence in which it is introduced.
- These strategies might include the types of textures that we provide to the patient.

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TREATMENT STRATEGIES

- Oral stage.
- Pharyngeal Stage.
- Esophageal Stage.

REDUCED LABIAL SEAL

- Use a straw rather than a spoon to present the bolus (best with pureed level foods or honey thick liquids).
- Touch or tap the lips with the spoon after the bolus is presented.
- If the patient does not become agitated attempt to close the lower lip with either the spoon or with your hands.

DECREASE LINGUAL MOBILITY (ANTERIOR-POSTEROR)

- Add pressure to the tongue when presenting the bolus.
- Use a straw to present the bolus outside the mouth and have the patient secure with their tongue and alternate locations.
- When safe place the bolus in various places in the oral cavity.
- When safe, place the bolus posterior in the oral cavity.

REDUCED LINGUAL PERISTALSIS

- Alternate solids with liquids.
- Consider "liquifying" solids .
- Use the straw outside the mouth on each side to provide the bolus.
- Consider downgrading the most difficult consistency (e.g. puree meats).

POCKETING/RESIDUE AFTER THE SWALLOW

- Provide liquids after each bite of solid and at least 120 cc at the end of the meal.
- Keep the patient upright after the meal.
- Reduce the size of the food bolus.
- Chop food before presenting bolus.

DELAYED INITIATION OF THE SWALLOW REFLEX

- If the patient does not become agitated physically tilt their head forward.
- Consider downgrading diet.
- Present bolus but do not provide until swallow is triggered.

REGURGITATION

- Have the patient upright 30 minutes before the meal, upright during the meal and 30 to 45 minutes after the meal.
- Feed the patient slowly with small bites and small sips.
- Consult the dietician to determine if some foods need to be removed from the diet.
- Consult nursing for potential medications to reduce reflux.

Adaptive Feeding Tools

- Dycem.
- non-slip dishes.
- plate guards.
- scoop dish.
- partitioned plates.

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Adapted Utensils:

- weighted utensils.
- angled utensils.
- built up handles
- rocker knife.
- Sporks.

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Adapted Cups:

- nosey cup.
- two handled cup.
- sippy cup.
- dysphagia cup.
- regulator cup.
- variety of flow-regulating cups.

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A word about adapted items....

- the more 'basic' the adaptation, the easier the transition to use.
- Adapted items that require multiple steps for application or use are more prone to fail the patient and the caregiver.
- Return demonstration of application and use by the caregiver is critical for success.

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A few more words about adapted items.....

- If possible, it is best to introduce the adapted item prior to the patient's entering stage 5-6-7 of their dementia.
- Yes, it is possible....

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Final Considerations

- Eating is as much a cognitive, social, and emotional activity as it is a physiologic one.
- For persons with dementia, the cognitive, social, and emotional aspects of eating cannot be ignored.
- Preservation of feeding and swallowing abilities, or minimizing their decline, is possible in persons with dementia.

WHEN TO DISCHARGE

- There is no change in their ability with skilled intervention.
- There has been a sentinel event in their medical condition that does not allow any benefit from skilled intervention.
- There is potential for improvement but therapeutic intervention exacerbates behavioral issues with the patient.

SOME THOUGHTS ON NON-ORAL FEEDING (PEG TUBE)

- PEG tube insertion may reduce lower esophageal sphincter pressure thereby increasing the risk of aspiration and do not eliminate oral secretion aspiration.
- There is also the risk of aspiration of stomach contents (Li, 2002).

- Weight loss and pressure ulcer development are associated with long term PEG tube feeding (Henderson, 1992).
- May increase suffering and discomfort thereby decreasing quality of life.
- PEG tube insertion does not eliminate the disease process that initially caused their dysphagia and/or the lack of appetite.

- Mechanical problems such as tube leakage, tube blockage, and tube malfunction can place the individual at risk for infection, skin excoriation, and increased pain at the site.

WHEN TO CONSIDER ENDING PO INTAKE

- Successive instances of aspiration pneumonia usually within a short period of time .
- MBS indicates clear aspiration with no evidence of compensatory strategies or modified consistencies reducing the risk.
- Signs/symptoms of aspiration occur daily over a period of time.

IN SUMMARY

- Caring for the individual with dysphagia and dementia is most effective when other disciplines including caregivers are involved in the treatment process.
- Always teach best practice for safety by example.
- The treatment plan should center on a diet that is safe but provides adequate nutrition and hydration.

