An Approach to End of Life Conversations in Dementia Care for Speech-Language Pathologists

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Learning Objectives

1. Increase knowledge of cognitive staging of dementia and correlation to dysphagia.
2. Identify behavioral indicators that may predict cognitive dysphagia and/or nutritional concerns.
3. Present a framework in order to increase knowledge and patient expectations without prior experience.
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Dementia

- Acquired brain disease characterized by a progressive decline in cognitive domains including:
  - Attention
  - Linguistic expression and comprehension
  - Executive functioning skills
  - Learning and memory
  - Visuospatial Skills
  - Memory

Prevalence

- US: 5.7 million
- Worldwide: 50 million
- 2030: 82 million
- 2050: 152 million

- Alzheimer’s accounts for 60-80% of cases
- 1 in 10 Americans 65+ has AD
- 1 in 3 elderly people will die from Alzheimer’s disease or another form of dementia

What does it look like to die from dementia?

healthy brain advanced alzheimer's
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**Assessment Framework**

1. Clinical Evaluation of Swallow
   - Instrumental Assessment, if indicated
2. Cognitive Staging
3. Education and Counseling

**1. Clinical Evaluation of Swallow**

1. Oral Care
   - Oral Health Assessment Tool (OHAT)
2. Oral Mech Exam
3. PO trials
4. Behavioral Feeding Assessment

**Clinical Evaluation of Swallow**

- Dementia Behavioral/Feeding Assessment Tools
  - Dementia Mealtime Assessment Tool (DMAT)
  - Edinburg Feeding Evaluation in Dementia Questionnaire (EdFED-Q)
### Observation Form

<table>
<thead>
<tr>
<th>Observation</th>
<th>Ability to Eat &amp; Drink</th>
<th>Not Seen</th>
<th>Seen Once</th>
<th>Seen Repeatedly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced ability to use cutlery (spoon, fork or knife)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced ability to get food onto cutlery (spoon, fork or knife)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced ability to cut meat or other foods</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced ability to identifiable food from plate</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Place foods or liquids around the table</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced ability using cups or glasses</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced ability seeing or identifying cups or glasses</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sips drinks when eating</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drinks all food without eating</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eats in a or a setting in a setting</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Observation</th>
<th>Preferences &amp; Choices</th>
<th>Not Seen</th>
<th>Seen Once</th>
<th>Seen Repeatedly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prefers sweet food or eats dessert / sweets first</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eats or drinks both</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Snacks with their partner</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers a snack / dessert first</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers a snack / dessert last</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefers a snack / dessert after meal</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Edinburgh Feeding Evaluation in Dementia Questionnaire (EDE-D-GU)

1. Does the patient require the use of feeding aids? [ ]
2. Does the patient require the use of specialized diet? [ ]
3. Does the patient require the use of specialized feeding equipment? [ ]
4. Does the patient require the use of specialized feeding methods? [ ]
5. Does the patient require the use of specialized feeding techniques? [ ]

### Notes

- Not seen = ability maintained
- Seen once = reduced ability observed at least once
- Seen repeatedly = reduced ability observed at least once

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2. Cognitive Staging

- Global Deterioration Scale (GDS)
- Functional Assessment Staging Tool (FAST)
- Brief Cognitive Rating Scale (BCRS)
- Allen Cognitive Levels (ACL)
3. Counseling and Education

- Current functioning and future expectations
- Involvement of interdisciplinary team members

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SPIKES Protocol

- S: Setting
- P: Perception
- I: Invitation
- K: Knowledge
- E: Empathy
- S: Strategy

Goals of Treatment

- Mitigate risk of decline
  - Medical
  - Nutritional
  - Quality of life
- Increase independence

Education
Anticipation
Preparation
Predictors of Pneumonia in Nursing Homes

1. Dependent for feeding
2. Mechanically altered diet
3. Weight loss
4. Tube fed
5. Suction use
6. Dysphagia
7. Poor Pulmonary Clearance (bedfast, dependence in bed, dependence in locomotion, COPD, CHF, & CVA)
8. Depressed Immune System (Weight Loss, UTIs, and age)

Indirect Interventions

• Modification:
  – Environmental
  – Auditory
  – Tactile (include senses)
  – Visual
  – Diet

Direct Interventions

• Spaced Retrieval Training
• Adaptive Equipment
• Training in hand-over-hand assistance

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GDS: 7 Cognitive-based dysphagia

- Dependence for oral care
- Dependence for feeding
- Oral apraxia
- Oral acceptance deficits
- Impaired attention for chewing/swallowing
- Confused feeding pattern attempts
- Unable to sustain nutrition and hydration needs by mouth

When Anticipation Becomes Reality

- Weight loss
- Severe dysphagia
- Dehydration
- Wounds
- Aspiration pneumonia
Next Steps

- Discussion with interdisciplinary team members.
- Family meeting for education and discussion regarding goals of care.

Case Study: Betty

- Betty is a 92 year old female admitted to short term rehab after being hospitalized due to sepsis secondary to UTI.
- Prior to hospitalization, Betty was living at a standalone ALF in “memory unit”. Betty has dementia and is primarily nonverbal and requires total assistance with all ADLs.
- Betty has had a 25 lb. weight loss in the last year.
- Betty was admitted to short term rehab on a regular/thin diet.

GDS = 6-7

- Cognitive/behavioral signs: texture aversion, oral acceptance deficit
- Oral signs: inability to masticate or form bolus.
Case Study: Johnny

Johnny was admitted to short term rehabilitation after being hospitalized for a right hip fracture. Johnny underwent a total hip replacement.

Johnny had a history of Alzheimer’s disease to which wife reported that he required assistance with bathing, walking, and was incontinent of bowel and bladder. Johnny was previously able to feed himself. Johnny usually ate softer foods at home like mashed potatoes and ground meats with gravy. Johnny was not oriented to time and did not recognize grandchildren.

Prior GDS = 6

Upon evaluation, Johnny is nonverbal and unable to self-feed. Johnny is positioned in a Broda chair for support.

Oral dysphagia signs: prolonged mastication and inability to form cohesive bolus.

Cognitive dysphagia signs: oral acceptance deficit, poor attention for swallowing and chewing, prolonged meal time.

Education and counseling

Therapeutic interventions put into place including diet modification and education and training of staff and family.

2 weeks later… patient became dehydrated and experienced increased difficulty swallowing.

- Increased clinical signs of pharyngeal dysphagia including coughing and choking with meals and severe apraxia of swallow.

- No improvements in cognition

Interdisciplinary team alerted by SLP to define goals of care.
References


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