Dementia & Dysphagia

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With slides from: *Shari Goo-Yoshino MS CCC-SLP;* Instructor, Department of Communication Sciences and Disorders, John A. Burns School of Medicine

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CIRCLE OF CARE FOR DEMENTIA

HALE KŪʻIKE

Pacific Islands Geriatric Education Center
Department of Geriatric Medicine
John A. Burns School of Medicine
University of Hawaii

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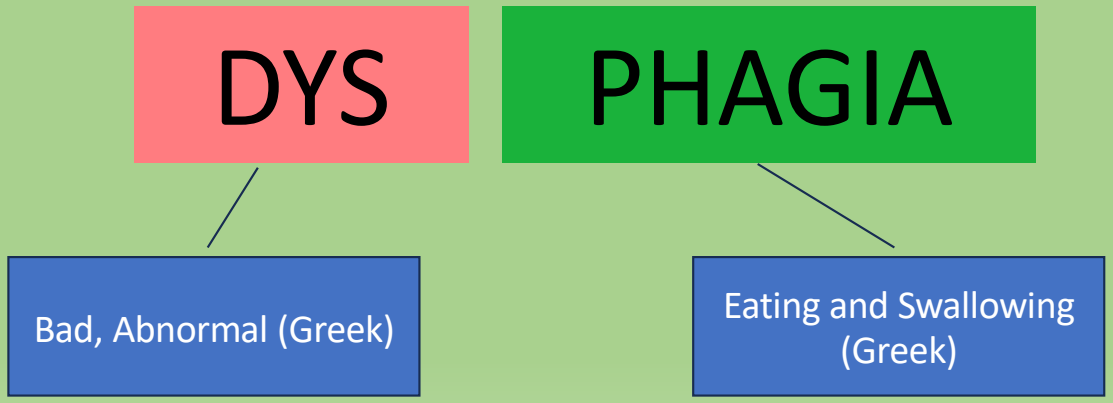
The speaker(s) have no relevant financial relationships to disclose.

Learning Objectives

Identify	The common symptoms and causes of dysphagia in older adults
Explain	The indications and functional outcomes of swallow evaluations
Learn	Techniques to optimize mealtime for different stages of dementia and dysphagia. Optimize
Optimize	How to prepare different consistencies of food and liquids to optimize enjoyment of meals.
Discuss	Issues regarding tube feeding for adults with dementia

What is Dysphagia?

- A condition with DIFFICULTY IN SWALLOWING food or liquid.



How Common is Dysphagia?

Highly prevalent

- Among residents living in assisted living or nursing facilities (40-60%),
- Related to dementia (13 to 57%),
- Related to Stroke (37 to 78%),
- Related to Parkinson's disease (35%-82%)

General Signs and Symptoms

- Coughing
- Choking or gagging
- Hoarse voice
- Drooling, “wet voice”
- Regurgitation
- Heartburn
- “Lump in the throat” sensation
- Effort to swallow
- Selective eating
- Pain with swallowing
- Or….No symptoms (silent aspiration)

Consequences

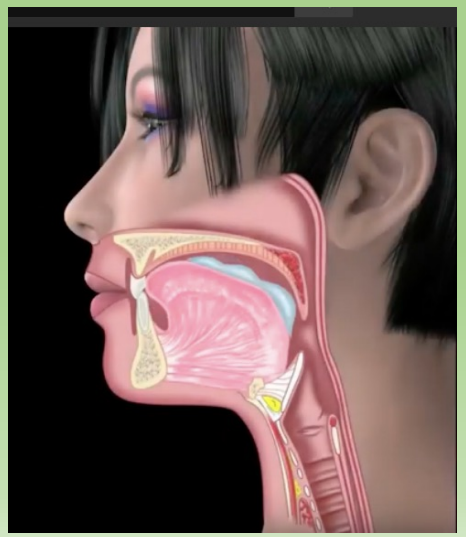
- Weight Loss
- Malnutrition
- Dehydration
- Choking or Aspiration (food goes down the “wind pipe” into lungs)
- Recurring aspiration pneumonia or fever,
- Compromised quality of life – life-style changes
- Usually, a symptom of other medical conditions (e.g. dementia, stroke, Parkinson’s)

Overview of Normal Swallowing Phases

1st: Oral: Liquid and food enter the mouth and are manipulated, chewed, mixed with saliva, and transferred into the pharynx (back of throat)

2nd Pharyngeal: Food and liquid enters and passes through the pharynx - Aspirationenters

3rd Esophageal: Passage of liquid and food through the esophagus and lower esophageal sphincter



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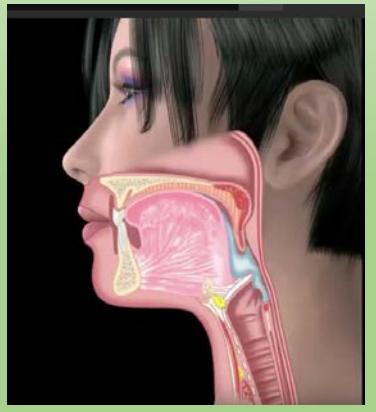

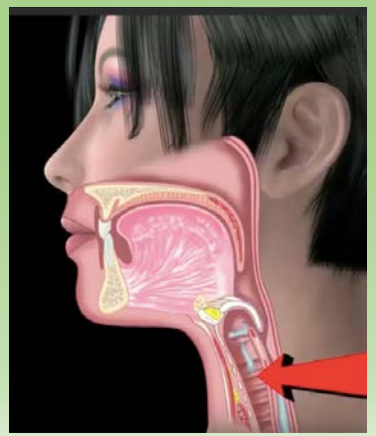

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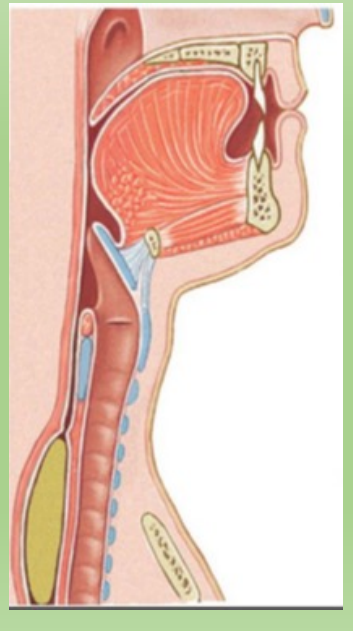
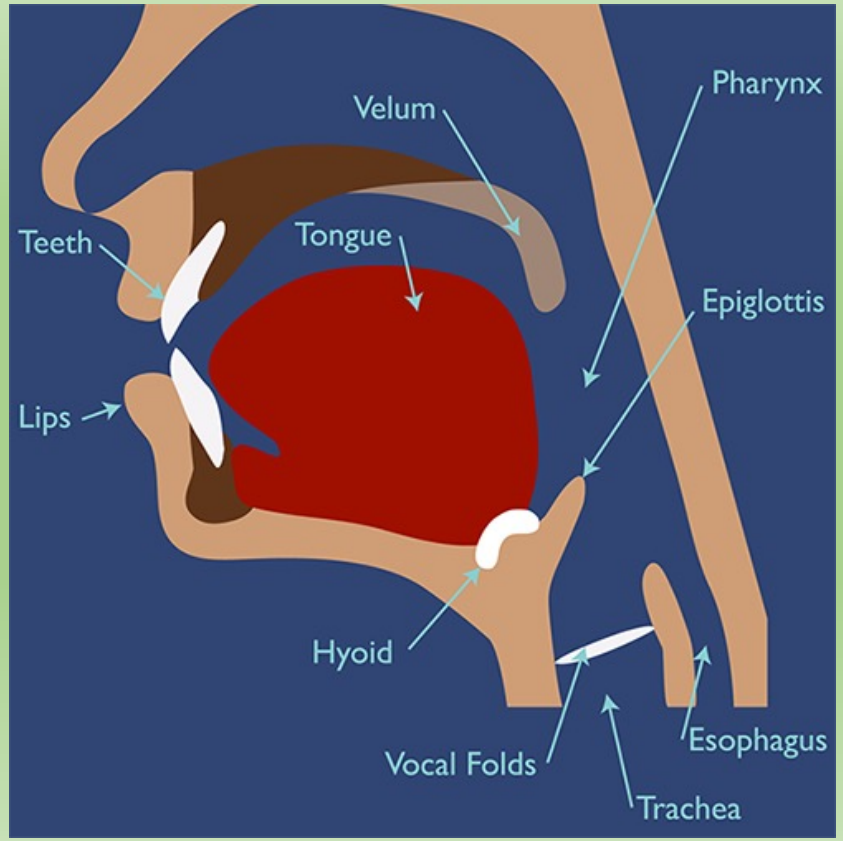


Oral and Pharyngeal Dysphagia



Signs and Symptoms

Holding food or liquid in mouth

Prolonged chewing

Spill of food or liquid from the lips or nasal cavity

Food or liquid remaining in the mouth “pocketing”

Drooling

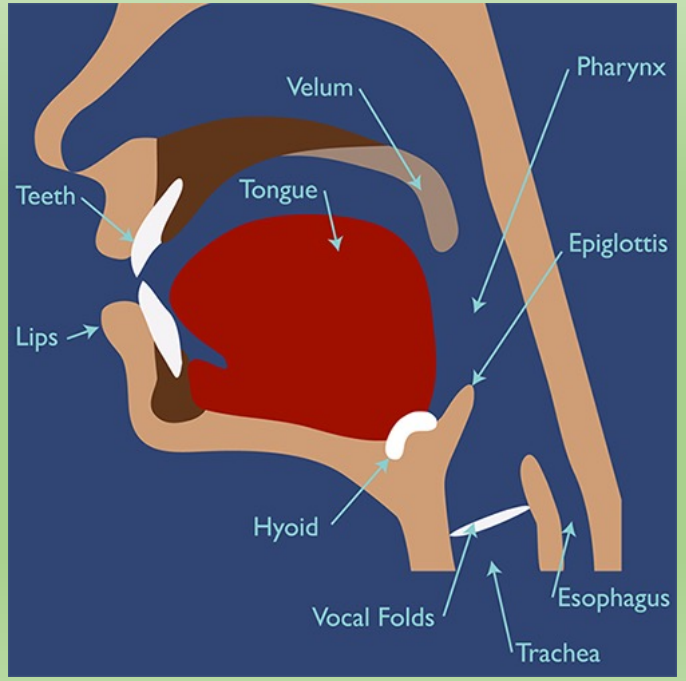
Dysarthria

Coughing during or shortly after eating and drinking

Complaints of food "sticking" in the throat

Wet voice during or after swallow

Causes of Oral and Pharyngeal Dysphagia



- Stroke, Dementia, Parkinson's, other neurological conditions
- Medications that cause:
  - Dry mouth
  - Sleepiness
  - Poor appetite
- Head and neck cancers
- Weakness and deconditioning

Clinical Swallow Evaluation

- Reviews the history and perception of the problem
- Examines oral structures and function
- Assesses swallowing (oral, pharyngeal phase, or both)
  - Tests different textures of food
  - Tests different consistencies of liquid

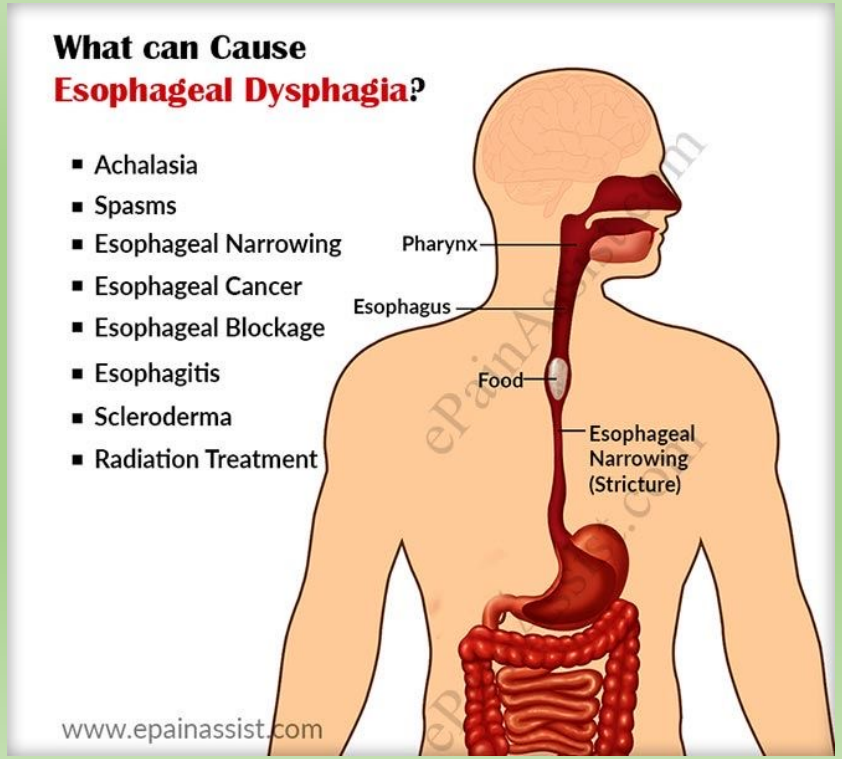
Referral: Speech-Language Pathologist (speech therapist)

Clinical Swallow Evaluation → Solutions

- Trials compensatory or rehabilitative techniques for swallowing
  - Determines optimum food and liquid textures by mouth
  - Strategies to facilitate safe and efficient swallowing
  - Counseling, education, and training
  - Personalized treatment plan
  - Referral for other services e.g., dietician, gastroenterologist
  - May consider if unsafe to take anything by mouth at all= NPO

- Does NOT determine presence or absence of aspiration or pharyngeal phase dysphagia -> Need to get video swallow evaluation

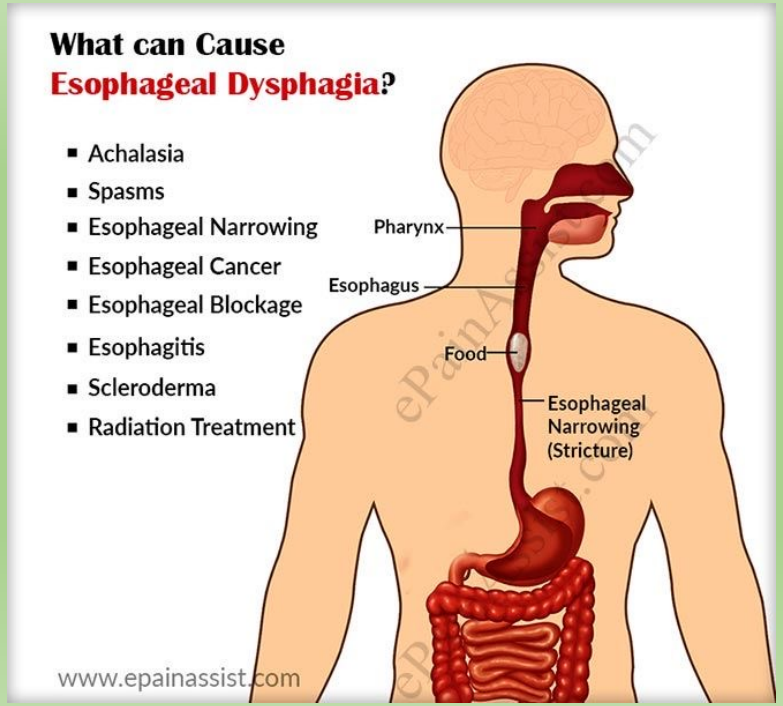
Esophageal Dysphagia



Signs and Symptoms:

- Pain with swallowing (odynophagia)
- Unable to swallow
- Feeling that food is stuck in your throat or chest behind your breastbone
- Hoarse
- Regurgitation (food backing up)
- Frequent heartburn or feeling acid backing up into your throat
- Having to cut food into smaller pieces or avoiding food because of trouble swallowing
- Frequent respiratory problems (asthma), or infection

Esophageal Dysphagia



Referral: Gastroenterologist

CAUSES

- Achalasia
  - esophageal motility disorder
- Esophageal spasms
  - trigger foods, stress, GERD
- Mechanical problems
  - cancer, radiation treatment, stricture,
  - Barrett's esophagus (prevented by early treatment of GERD)
- Weakness and deconditioning

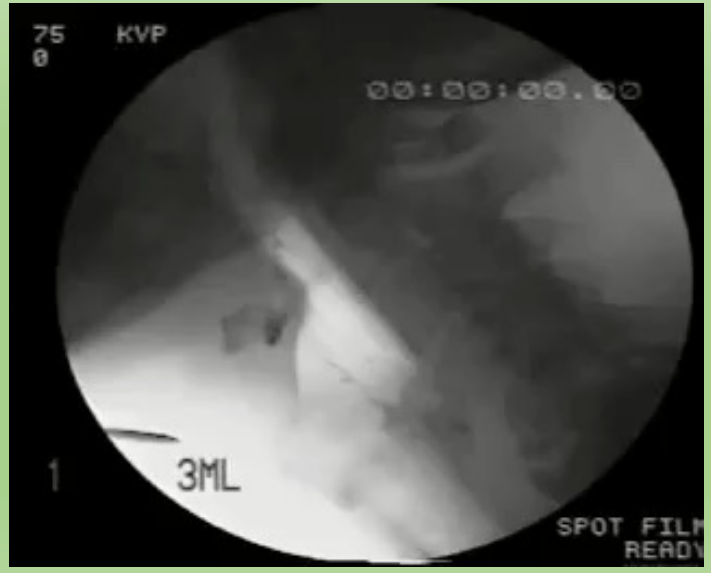
Indications for Video Swallow Evaluations

- Symptoms or signs of pharyngeal phase dysphagia
- Uncertainty in safety and efficiency of swallowing for nutrition, pulmonary health, and airway safety (aspiration, choking)
- History of medical conditions associated with high risk for dysphagia and aspiration
- Previously identified dysphagia with a suspected change in swallow function that may change recommendations

Information guides management and treatment

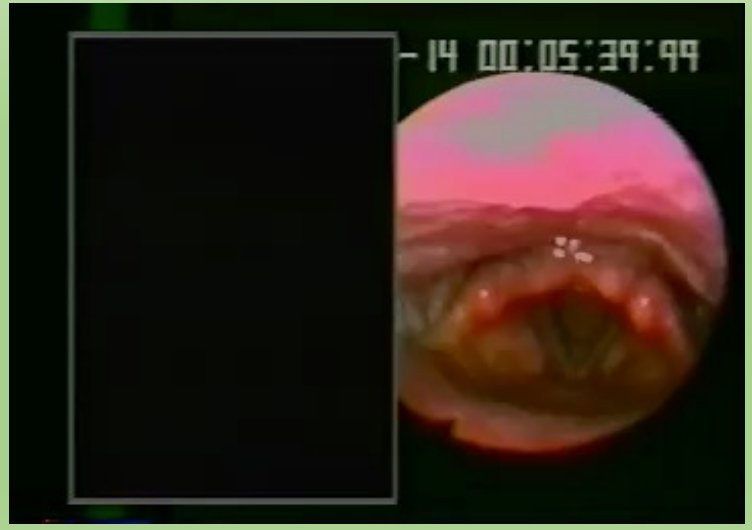
Your Doctor can help you determine if this is needed.

Instrumental Swallow Evaluations - Video fluoroscopic Swallow Study/Modified Barium Swallow Study



- Provides direct visualization of **oral, pharyngeal, and upper esophageal structures and function**
- Assess swallow of food and liquid with barium
- Observe flow and clearance of materials from **mouth to entrance into esophagus**
- Determine influence of diet changes and compensatory strategies on swallow efficiency and safety

Instrumental Swallow Evaluations - Fiberoptic Endoscopic Evaluation of Swallow



- Provides direct visualization of **pharyngeal structures and function**
- Assess swallow of food and liquid
- Observe flow and clearance of materials through **pharynx**
- Determine influence of diet changes and compensatory strategies on swallow efficiency and safety

Instrumental Swallow Evaluation Outcomes

- Diagnosis of oral and **pharyngeal** phase dysphagia
- Detection of **aspiration**
- Optimum food and liquid textures by mouth / Consider NPO
- Strategies to facilitate safe and efficient swallowing
- Counseling, education, and training **(with biofeedback**)
- Referral for other services e.g., dietician, gastroenterologist
- Personalized treatment plan

Management and Treatment Options – Person-Centered Care

Restorative Exercises

Oral motor swallowing exercises

Expiratory muscle strength training

Neuromuscular electrical stimulation

Thermal-tactile stimulation

Feeding/Behavioral Strategies

Optimal alertness

Head and body positioning

Rate of feeding - Bolus size and placement

Swallow maneuvers

Counseling

Education

Training

Dietary Considerations

Appropriate texture

Preferred foods and drinks

Attractive - Proper temperature

Smaller, more frequent meals

Accessible snacks

Environmental Modifications

Maintain meal routines

Seating to improve posture

Calm environment - Reduce distractions

Support self-feeding – Consistent prompts

Pleasant exchanges – Optimize communication

Considerations for Gastric Feeding Tubes

BENEFITS

- Easier, less time, ensure caloric intake
- Only benefits those NOT in the last stage of illness, such as:
  - acute stroke,
  - head trauma
  - critically ill with good chance of recovery,
  - Head and neck CA
  - ALS
  - young patients,
  - more functional patients.

DOES NOT HELP IN END-STAGE DISEASE (Alzheimer's, Parkinson's, Terminal cancer, CVA without improvement, PVS, poor prognosis)

- DOES NOT Prolong life, gain weight
- DOES NOT Prevent aspiration
- DOES NOT help with pressure sores
- DOES NOT improve functional status

RISKS

- Decreased QOL (isolation, decreased human contact, denied gratification of food, restraints)
- Nausea, Vomiting, Diarrhea
- Complications: Bleeding, Infection, Skin irritation, Leaking, Blocked, Falling out, Pulled out
- Increased risk for Pressure Ulcers
- More likely to get aspiration pneumonia
- More likely to get fluid overload

Decision making process

- Find out what is most important to the person at this time in life.
- Ask: Does tube feeding help meet those goals?
- Consider if the person is in their end-stage of their disease process.
- The natural dying process is not necessarily painful or uncomfortable (naturally a smaller appetite, thus only desire a small amount of food/drink).
- Consider both the medical facts, and personal subjective elements
- A time-limited trial is always an option.
- The decision to either institute artificial feedings or to withhold them rarely needs to be made emergently.
- Focus feeding for quality of life, rather than calories. Small amounts for pleasure and taste.

Slide Credit: Christina Bell, MD

Alternatives & Suggestions

- Treat conditions that cause poor appetite: constipation, depression, infection
- Stop medicines that make eating problems worse
  - Antipsychotics/ Antianxiety
  - Sleeping pills
  - Bladder Control meds
  - Alendronate
  - Donepezil
- Dental Care
- Careful Hand feeding, favorite foods for QOL feeding
- Hospice referral
- Other ways to show love (massage, read, music)

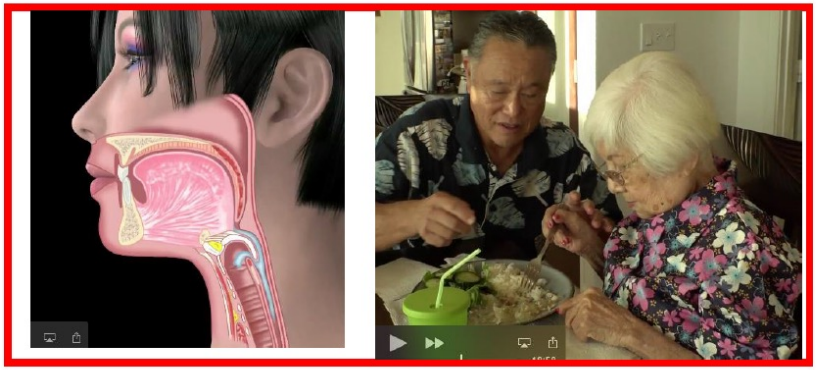
Caregiver Video

From JABSOM Department of Geriatric Medicine

Videos available in three languages

CAREGIVER EMPOWERMENT SERIES

DYSPHAGIA (SWALLOWING DIFFICULTIES) AND AGING



Designed for caregivers helping someone with dysphagia, the 19-minute program includes information on the phases of dysphagia, esophageal reflux and lifestyle measures to manage it, aspiration risk reduction, dietary considerations, modifying food and liquid textures, dysphagia and dementia, and end of life concerns.

YouTube

English, Chuukese, Ilocano and Samoan versions can be viewed at: *http://geriatrics.jabsom.hawaii.edu/resources/*
or scan the QR code on the right.

For inquiries and copies, please contact:
Department of Geriatric Medicine
(808) 523-8461

Made possible by a grant from
The Health Resources and Services Administration (HRSA)
Geriatrics Workforce Enhancement Program

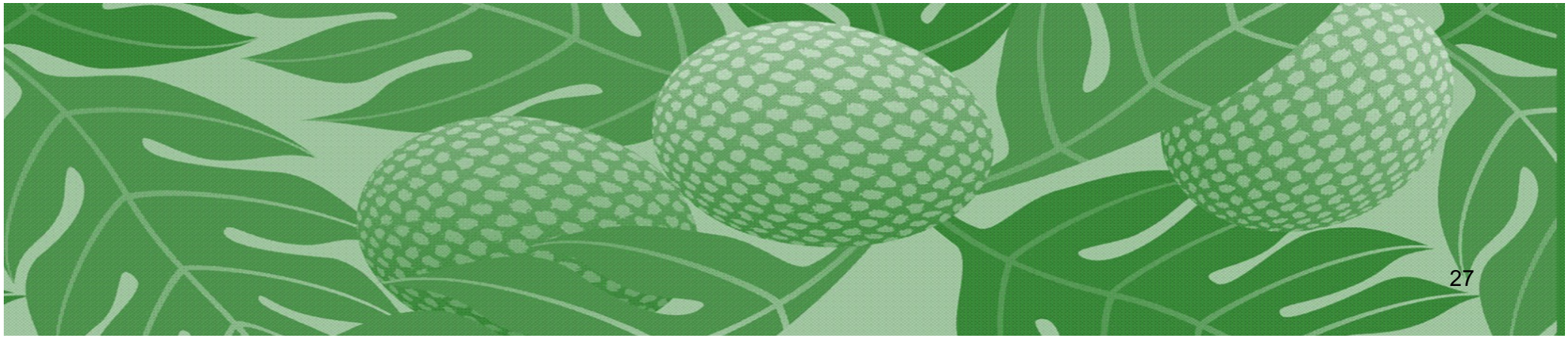
HALE KŪ'IKE

Dementia and Dysphagia

Dorothy Arriola Colby

Hale Ku'ike Director of Community Engagement
Positive Approach to Care Certified Trainer

April 22, 2023 for Catholic Charities Hawaii



Eating is an IMPORTANT part of our day…

Help to make it DELICIOUS!

….Even if DYSPHAGIA is in the picture

As dementia progresses, watch for changes in eating…

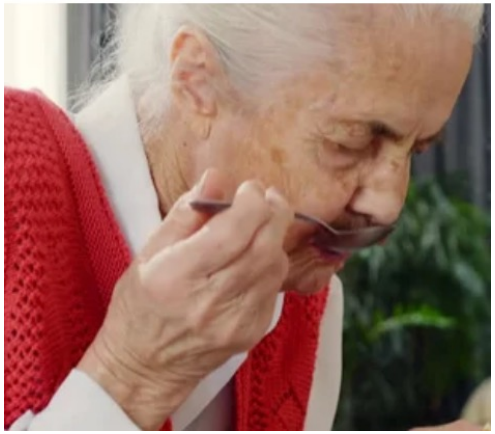
- Change in health
- Denture or mouth problem
- Drug interactions

OR

- Is it advancing dementia that is changing abilities?

What does successful eating require?

In addition to fine motor finger skills, eating requires fine oral motor skills.



Muscle control

- Mouth
- Jaw
- Lips
- Tongue
- Cheeks
- Throat

Eating Skills

- Sucking
- Biting
- Crunching
- Licking
- Chewing
- Swallowing

Matching up changes in eating & nutrition with progression of dementia

- Sapphires – True Blue – Slower BUT Fine
- Diamonds – Repeats & Routines, Cutting
- Emeralds – Going – Time Travel – Where?
- Ambers – In the moment - Sensations
- Rubies – Stop & Go – No Fine Control
- Pearls – Hidden in a Shell - Immobile

Dysphagia often a part of living in the later Ruby and Pearl GEM states

Ruby Changes

- Using hands - not utensils and fingers
- Dropping & spilling - Less aware of position in space – moves ‘whole’ body or body part
- Communicates needs with ‘behaviors’
- Can be hypersensitive around mouth & fingers
- Can’t stop moving or can’t get going
- Monocular vision – lacks figure-ground & depth perception
- May be burning more calories – limited proteins
- Trouble organizing chewing to swallowing – pocketing – holding but not eating or drinking

Main Ruby Messages

- Copy not imitate
- SLOW down
- Simplify
- Hand-under-hand assist
- Ask for only one thing at a time
- Decrease duration – increase frequency

Ruby Issues

Common Concerns

- Weight loss
- Dehydration
- Limited items liked
- Refusals
- Spillage
- Not sitting down to eat
- Not waking up to eat
- Not able to feed self
- Pocketing
- Sitting

Possible Changes

- Walking snacks
- Super ’sweeting’
- Limit textures
- Hand under hand assist
- Work on transitions
- Use spoon use ‘thick’ liquids versus ‘solid’ items
- Cups with covers & straws
- 6-8 ‘meals’ a day
- Smaller bites – 5 bites then a drink

Teepa Snow helps Lucille eat using Hand Under Hand assistance

- Teepa's hand is the under hand, providing support and guidance.
- Lucille's hand is on top and participating with bringing the food to her mouth, and can give Teepa feedback
- Notice how Lucille opens her mouth BEFORE the spoon reaches it. She knows it is coming.
- Notice how Teepa uses her left hand to make the bowl move to make it easier for her right hand.
- Lucille is feeding herself with fine motor assistance from Teepa.

Pearl Changes

- Limited intake & drinking
- Problems with swallowing (dysphagia)
- Limited ability to fight infections
- Limited interest
- We will have to assist
- It is tempting to try to ‘feed’
- It is tempting to put too much in at a time
- Reflexes dominate

Main Pearl Messages

- Prepare to - Let It GO!
- Peaceful time – smells, sights, sounds
- HELP EAT – don't feed
- Alert = can eat *NOT* alert = *DON'T* eat
- 'Tastes' *not* nourishment or hydration

Pearl Issues

Common Concerns

- Won't open mouth
- Won't swallow
- Chokes – doesn't choke
- Coughs – doesn't cough
- Gets pneumonia
- Muscle wasting
- Bite reflex, tongue thrust, grinding of teeth
- Contractures
- Sleeping

Possible Changes

- Hand to shoulder & hand under forearm or wrist
- 'empty bite' to mouth
- Speech consult
- Limit offerings
- Protein smoothies with fluids
- Consult an OT/PT for seating options & cues
- STOP… love the person… let them know you get it

Final message related to food and drink

With dementia, it is about our relationship

NOT about getting it in & getting it done

Making Accommodations for changing skill

Plates and Utensils

- Adaptive plates with lips/rims
- Plates with suction on bottom to hold in place
- Sectioned plates
- Weighted utensils
- Fatter grips on utensils
- Bendable utensils
- Cups with texture for gripping
- Mugs with large handle openings
- Cups/mugs with covers

Changes in food textures & how offered

- Thickened liquids
- Chopped, fine chopped, or pureed food
- Finger foods
- Walk and chew foods
- Hands on help to get started
- Hand Under Hand help throughout the whole meal

Help me be successful with the skills I still have!

Chop it or puree it, but don't forget to make it delicious!

Modified consistencies

- Chopped – no need to take bites or cut it up
- Fine chopped – no need to chew much at all
- Pureed – no chewing needed at all
- Thickened liquids
  - Thin liquid – just like water
  - Nectar – thick as guava juice
  - Honey – thick as honey
  - Pudding – thick like pudding

Make it delicious!

Ways to add in flavor

- Liquids for pureeing to add flavor
  - Chicken or beef broth
  - Condensed soups
  - Gravy
- Other flavor boosters
  - Fat = Flavor!!
  - A bit of butter, parmesan cheese
  - Creamy additions – Greek yogurt
  - Sweet additions– honey, jelly, jam
- Taste before serving!
  - Does it need more salt?
  - Does it need sweetness?

Dining & Dementia Resources

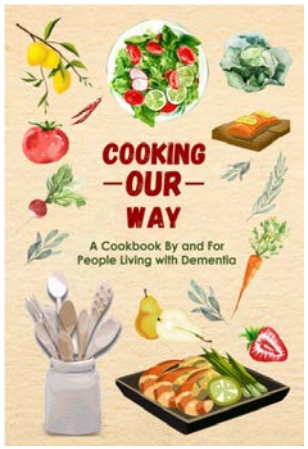
Positive Approach to Care
www.teepasnow.com
Dementia Education and Skill Building Resources

Adaptive plates, cups, and utensils
Longs / CVS • Pharmacy section
Amazon • www.amazon.com
The Wright Stuff • www.thewrightstuff.com
* Good Grips brand is bendable

Clothing protectors
Buck and Buck • www.buckandbuck.com
Adaptive clothing, including clothing protectors

Dining Scarf
Available on Etsy, www.etsy.com
search words “dignity scarf, or sew your own!

More Dining & Dementia Resources

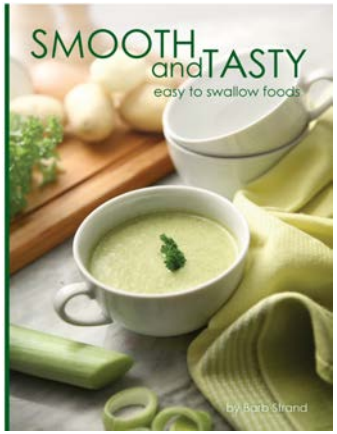


Cookbook by and for People Living with Dementia

Published by The Dementia Action Alliance

The FREE PDF cookbook includes information about organizing your kitchen to make it dementia-friendly, nutritional and healthy diet information, protective kitchen aides and much more.

https://daanow.org/wp-content/uploads/2023/07/CookingOurWay_062623-1.pdf



Smooth and Tasty– easy to swallow foods

By Barbara Strand

"We want to share the lessons we have learned while creating high calorie, nutrient-dense, and easy-to swallow foods. Whether you are dealing with cancer, stroke, dysphagia, teeth problems or have lost weight for any reason, this cookbook will make your life a little easier and your food tastier."

Available for purchase on Amazon