



# Speech Pathology and Huntington's Disease: Facilitating Safety and Comfort While Maintaining Quality of Life.

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# Presenter Disclosures

**Julie M Pitti**

**The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:**

No relationships to disclose  
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Huntington's Disease  
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# Safety, Comfort, and Quality of Life!

- What is a Speech Pathologist?
- How we can help
- Swallowing difficulties and strategies to maintain QOL
- Communication and ways to improve it
- Signs you may need some help

# What is a Speech Language Pathologist (SLP)?

- Master's degree in Speech Pathology
- Assess and treat people with swallowing difficulties
- Assess and treat people with speech, language, voice, and cognitive difficulties
- Work in hospitals, skilled nursing facilities, acute rehabilitation centers, schools, and specialty clinics
- Work with people who have had strokes, head injuries, or have progressive neuromuscular diseases such as ALS and Huntington's disease

## How We Can Help People and families with HD

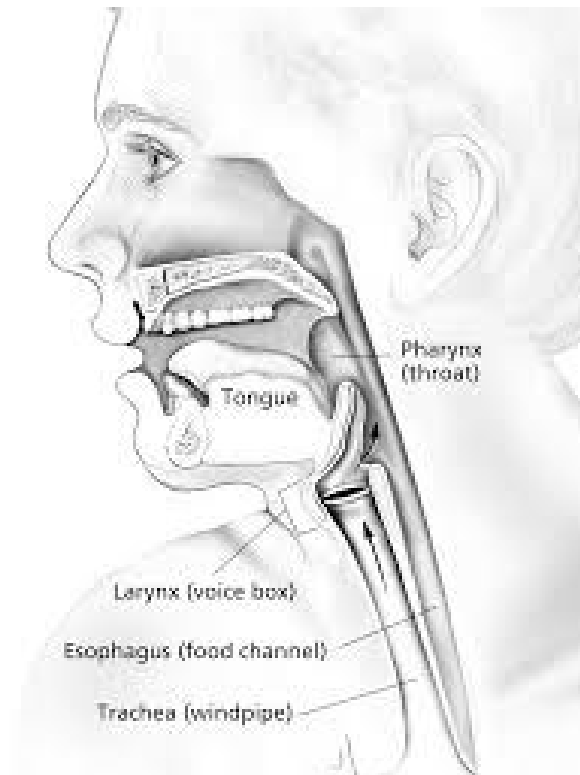
- Assess swallow function
- Assess speech, language and cognition
- Offer guidance for safe swallowing
- Make suggestions for efficient nutrition
- Assist with effective communication
- Support

# Assessment of Swallow Function

- Interview
  - How do you feel about your swallow function?
  - Are you coughing or choking during meals?
  - If yes, does it happen with solids or liquids? Or both?
  - How often? And when?
- Oral Motor Exam
  - Cranial Nerves
  - Voice and Cough Strength
  - Breath Support “ah”
  - Articulator Agility (tongue, lips)
- Food Trials
- Instrumental Exam-Modified Barium Swallow Study

# Normal Swallow Function

- Three Phases of Swallow
  - Oral phase
    - Chewing
    - Bolus formation
  - Pharyngeal phase
    - Swallow reflex
    - Move food to esophagus
  - Esophageal phase
    - Food to stomach





## Common Swallowing Difficulties

- Poor oral coordination of tongue and lips
- Incomplete chewing/moving food to back of mouth
- Holding food or liquids for long time prior to swallow initiation
- Drooling or food spillage from mouth
- Incomplete swallowing-leaving food residue
- Impulsivity/difficulty controlling amount of food or liquid intake
- Incoordination of swallowing and breathing
- Talking while eating
- Inattention to task of eating (distracted by TV or other activities)

## Signs of Difficulty Swallowing

- Coughing/Strangling
- Choking
- Wet sounding voice after swallow
- Wet breath sounds
- Frequent throat clearing
- Consistent weight loss
- Frequent congestion
- Coughing when not eating (saliva mismanagement)

## Safe Swallow Guidelines

- Keep a journal of swallowing difficulties-What food? Where? Situation? When?
- Keep mealtimes predictable- same times, similar situations)
- Sit upright with head support if needed
- Reduce distractions-turn off TV, keep conversation to a minimum
- Use a straw or cup with a lid
- Use weighted utensils and plastic dishes with rims
- Put utensils down between bites to slow down and reduce “packing”
- Cough every few bites to remove residue, if needed
- Sip water throughout day to initiate a swallow (helps control excess saliva)

## Diet Modifications

- Cook foods a little longer to soften them
  - Use crock pot
  - Use leaner cuts of meat
  - Casseroles
- Chop foods or finely grind them
- Add gravies, sauces and condiments
  - Mayonnaise, sour cream, butter, ketchup
- Puree foods (blenderize) if chewing is difficult
- Add high calorie, nutrient dense foods to blender (shakes & soups)
- Thicken liquids if coughing consistently while drinking
- Swap hard foods for soft ones-brownies for Oreos, etc.

## Safety and Comfort While Swallowing

- Oral Care! Keep your mouth clean!
- Modify diet as a last resort- People tend to have specific food preferences.
- Understand the risks of aspiration –sending food or liquids “down the wrong pipe”
- Preserve Quality of Life- Often persons with HD want to eat foods that seem unsafe which may make caregivers uncomfortable. It’s important that they are able to do so--at least occasionally.

## Communication – Stay Connected

- Engagement from both communication partners-the listener and the speaker is necessary for effective communication.
- Lack of communication can cause a person with HD to have feelings of depression, frustration, and isolation.
- To achieve effective communication the listener must consciously accept the responsibility for the conversation exchange.

# Communication Components

- Speech
  - Articulation
  - Breath Support/Phonation
  - Coordination
- Language
  - Expressive
  - Receptive
- Cognition
  - Attention
  - Memory
  - Problem Solving

# Speech Production Difficulties and Intelligibility

- Reduced breath support
  - hoarse, harsh or strangled vocal quality
- Inappropriate rate, rhythm, and pitch of speech
  - Too fast, too slow, monotone, inappropriate stress on words
- Imprecise articulation
  - Unclear pronunciation of sounds



# Strategies for Increased Speech Intelligibility

- Speak slower
  - One word at a time, if needed
- Shorten utterances
  - Practice breathing exercises
- Exaggerate oral postures during speech
  - Move that tongue, purse those lips!

## Language and Cognitive Skills

- Difficulty initiating conversation
  - Difficulty putting thoughts into words
- Limited ability to respond in conversation
  - Word finding
- Difficulty understanding complex information
  - Slow response time
- Difficulty learning new information
  - Poor short term memory
- Poor attention and concentration abilities
- Reduced organizational skills
- Reduced ability to reason and problem solve

## More on Cognition...

- Because Huntington's is a degenerative brain disorder, these difficulties occur randomly as the disease progresses. This unpredictability can be frustrating for the person with HD.
- As a caregiver, it is important to understand that the person with HD has no control over this; they are not being stubborn or consciously choosing to not remember a task.

# Strategies for Effective Communication for Speaker and Listener

- Indicate need or desire for communication
  - Same room
  - Face-to-face
  - Touch arm or shoulder to get attention
- Speak slower
- Repeat message
- Rephrase message
- Simplify message

Remember the main goal is to get message across. So...

## More Effective Communication

- Use yes and no questions
  - Broad to specific decision tree- Hungry? Pizza or Sandwich?
- Rehearse common conversational exchanges
  - Daily activities /tasks
- Monitor perseverative behavior
  - “We’re changing topics now...”
- Allow adequate time for communication
- Reduce distractions
- Gestures and facial expression
- Get main idea
- Keep environment predictable

# Assistive Communication

- Communication devices
  - Smart phones/tablets
  - Apps for communication
  - Texting and email
- Low tech
  - Reminder notebook
  - Calendars
  - Memory book
  - Communication boards

# When to Contact a Speech Language Pathologist

- Earlier the better-before there is a problem to establish a plan as disease progresses
- When you begin to see changes in
  - Communication
    - Speaking
    - Understanding
  - Swallowing
    - Coughing or choking more
    - Any change in dietary habits
    - Weight loss

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