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 or list
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
References


• Stewart, C. (2012). Dysphagia Symptoms and Treatment in Huntington’s Disease: Review. SIG 13 Perspectives on Swallowing and Swallowing Disorders (Dysphagia), 21(4), 126-134.


• http://www.kumc.edu/hospital/huntington's /communication.html