Stronger together!

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European Conference on Huntingtons Disease

Nutrition, eating and swallowing –
needs, challenges and solutions Workshop

SWALLOWING DIFFICULTIES IN HD

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The role of Speech Pathologist in HD

Multidisciplinary TEAM working

Huntington's disease

- Swallow - dysphagia
- Speech and Voice - dysarthria
- Language and Communication
- Cognition

Dysphagia

Swallowing difficulties (Dysphagia):
difficulty passing food or liquid from the mouth to the stomach.

- It is a **common** problem in Huntington's disease
- It can occur since the **early stages**
- It gets worse as the disease **progresses**
- It is influenced by the movement, cognitive and behavioral problems
- It raises the risks of **aspiration pneumonia**, **airway obstruction**, **dehydration** and **malnutrition**

Normal Swallowing phases

PRE-ORAL and ORAL phase

Looking at the food
Salivating
Using utensils
Putting food into the mouth
Chewing
Bolus formation

PHARYNGEAL phase

Swallow reflex
Closure of the Larynx
Move food to esophagus

ESOPHAGEAL phase

Food to stomach

Common difficulties in HD

- Inattention to the task of eating (distracted by TV or other activities)
- Impulsivity
- Difficulty controlling amount of food or liquid intake
- Tachyphagia (excessively rapid eating)
- Postural instability and Hyperextension of neck and trunk
- Difficulty in handling cutlery and cups

- Poor oral coordination of tongue and lips
- Poor lip closure
- Facial/lingual chorea
- Drooling or dry mouth
- Incomplete chewing
- Difficult moving food to the back of mouth
- Holding food or liquids for long time prior to swallow initiation

Common difficulties in HD

- Incomplete swallowing-leaving food residue
- Incoordination of swallowing and breathing
- Talking while eating/Involuntary phonation during swallowing
- Laryngeal chorea
- Delayed and repetitive swallow
- Prolonged laryngeal elevation
- Penetration or aspiration of food or liquids (cough, throat clearing, change in voice quality)
- Silent aspiration (no cough)
- Choking

Signs you might need to contact a SLP

Earlier the better-before there is a problem to establish a plan as disease progresses

- Collection of food at the side or on the roof of the mouth
- Spitting food out of the mouth
- Regurgitation of material through mouth or nose
- Frequent throat clearing
- Wet voice quality after swallowing
- Coughing (during or after meals, when not eating – saliva)
- Choking
- Changes in dietary habits (difficulty with different food textures or liquids)
- Weight loss
- Recurrent episodes of pneumonia

Swallowing Assessment

Patient and Caregiver Interview
Communication status
Nutrition and hydration status
Effects of behavior and cognitive status/factors
Alertness levels
Ability to participate and co-operate

Clinical Swallowing Evaluation
Oro-facial examination (cranial nerve assessment, motor skills…)
Voice and Cough Strength
Articulator Agility (tongue, lips…)
Respiratory status and Posture
Saliva management (spontaneous swallow)
Oral hygiene
Liquid and food trials

Mealtime observation (if possible)

Instrumental Swallowing Assessment
Videofluoroscopic swallowing study (VFSS)
Fiberoptic endoscopic evaluation of swallowing (FEES)

Management of dysphagia in HD

Maximizing **Safety** and **Quality of Life**
Tailored therapy to individual patient characteristics!

Environment

- Eat in a relaxed comfortable environment
- Keep mealtimes predictable (same times, similar situations)
- Reduce distractions (TV, conversation ect.)
- Maintain an upright position (as near 90 degrees as possible) with head support if needed, during and after eating (30-45 min)
- Never administer fluids, solids or medications while the person is lying down or in a reclining position

Mealtime Equipment/Utensils

- Double-handed cup or dysphagic mug
- Weighted utensils or hand strap or grip cutlery
- Plastic dishes with rims
- DO NOT drink with a straw (unless specifically advised by your therapist)

Management of dysphagia in HD

Pacing and Feeding Strategies

- Cough every few bites to remove residue, if needed
- Do not introduce more food into the person's mouth until the previous mouthful has been swallowed
- Take a small amount of food and place it into the person's mouth
- Sip water throughout day to initiate a swallow (to control excess saliva)
- At the end of the meal, check the inside of the cheek for any food that may have been pocketed

Postural/Position Techniques

Postural strategies are used to help change the way bolus flows through the swallowing mechanism (identified by the SLP during clinical and instrumental evaluations).

Swallowing Maneuvers

They are used to change the swallow physiology (identified by the SLP during clinical and instrumental evaluations).

Management of dysphagia in HD

Sensory Stimulation
Thermal-tactile stimulation applied to the tongue, around the mouth, and/or in the oropharynx.

Oral-Motor Therapy
To improve the range of motion of the lips, tongue, and jaw, to improve coordination, to improve vocal fold adduction, laryngeal elevation, or tongue base retraction.

Oral care/Oral Hygiene
Oral hygiene and dental care are **important**. Secretions that accumulate on the tongue and palate reduce oral sensitivity and promote bacterial growth – risk factor for pneumonia (swallow of saliva continues also during artificial tube feeding).

Diet modification
Alterations to the consistency of foods and/ or liquids based on the dysphagia level.

Diet Restrictions, Modifications, Recommendations

Food to avoid !

Food with poor consistency (e.g. biscuits)
Vegetables or fruit with skins difficult to be removed with the tongue
Small, coarse and hard foods (peanuts, fruit seeds ect.)
Over-spiced food
Fish with bones unless filleted completely
Tough or stringy cuts of meat
Shredded vegetables like carrots and lettuce
Mixing food textures (e.g., rice soup)

If required, **liquids** should be altered with thickener (thin, nectar thick, honey thick, pudding thick) or it may be altered how they are swallowed (i.e., use of teaspoon)

Diet Restrictions, Modifications, Recommendations

Texture modified diet
(according to International Dysphagia Diet Standardisation Initiative -IDDSI)

- **Soft & Bite-sized:** soft foods that requires some chewing
- **Minced &Moist:** tiny piecies of food that requires minimal chewing
- **Pureed:** no chewing is required

Add oil and sauces to make food more viscous

Always adjust caloric intake and nutritional composition of the texture modified diet with a Nutritionist

Difficulty swallowing medications (pills, tablet…): identify with the physician alternative formulation (e.g. liquid)/routes of administration, or if it is possible to alter the solid drug

References

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