

Strategies for Speaking and Eating with HD

By Jeanne E. Thomson, M.S., CCC-SLP

People with HD face a progressive degeneration in their ability to speak, communicate, eat and swallow. Management strategies have been developed to help individuals with HD and their caregivers to maintain a higher quality of life during the progression of the disease.

Managing communication in HD

Communication difficulties are common in persons affected by Huntington's Disease and are a leading cause of depression.

People with HD often experience changes in memory, judgment and problem-solving (cognition) as well as a breakdown or impairment in their ability to speak (dysarthria). While HD has a progressive, debilitating effect on a person's ability to communicate, there are techniques that assist and augment understanding. Your doctor may have additional suggestions or may recommend a skilled speech language pathologist who can perform a comprehensive language assessment.

COGNITION MANAGEMENT STRATEGIES

- Maintain a structured environment with established daily routines
- Use calendars and to-do lists
- Ask that information be kept concise and simple
- Use a journal to record feelings and perceptions
- Have important information written down
- Keep written information on new people and events

Difficulties with speech

People with Huntington's Disease often find it hard to make themselves understood. Slurring of the speech is a common problem. Coordinating breathing and speaking may become difficult due to sudden involuntary movements (tics). Unnatural hesitations while speaking as well as sudden changes in volume may occur. The rhythm and rate of speech are sometimes affected. These are a few management strategies to help patients and caregivers improve the quality of their communication.

SPEAKING TIPS FOR THE PERSON WITH HD

- Watch your listener for signs of misunderstanding
- Restate your message using different words (rephrasing)
- Consider using a picture, alphabet or phrase board
- Ask a speech therapist for speaking drills to help maintain your rate and rhythm of speech

COMMUNICATING STRATEGIES FOR CAREGIVERS

- Stop the affected individual and ask them to repeat themselves
- Suggest to the individual with HD that they rephrase their message
- Set up a reliable yes/no system or code

It is always a good idea to introduce and gradually begin to use a new communications tool or strategy before the person with HD actually needs it. In that way, the person with HD will be comfortable using the tool or strategy and will be able to continue to communicate.

Improving eating and swallowing in HD

Difficulty with eating and swallowing (dysphagia) is a common complication of HD. This creates not only an uncomfortable situation, but one that can be life-threatening. Food that is swallowed without adequate chewing; coughing caused by food entering the air passages; respiratory tics (hiccups) and air being swallowed all undermine the ability of a person with HD to eat and enjoy meals.

Paradoxically, a person with HD needs more calories to maintain a healthy weight than a person without HD.

The challenge of maintaining adequate intake and safety during meals can be daunting. It is recommended that the person with HD or a family member/caregiver should consult with a licensed speech language pathologist for a full eating assessment. These are a few techniques to improve the mealtime experience.

EATING TIPS FOR THE PERSON WITH HD

- Slow down the pace of eating. Put the utensil down between mouthfuls.
- Use a “commuter” cup with a lid or a straw to limit the amount of liquid to reduce the chance of choking.
- Try weighted dishes and plates with higher edges to make eating easier.
- Select utensils with bigger, softer handles, like those designed for people with arthritis.

MEALTIME STRATEGIES FOR CAREGIVERS

- Include more fat and calories to maintain weight during the early and middle stages of the illness.
- Chop foods to compensate for lack of chewing.
- Reduce the use of liquids to “wash down” foods. Try purees, such as applesauce.

Because of the danger of choking, all caregivers should know the Heimlich maneuver: a simple technique that dislodges food caught in the throat. Your local hospital, Red Cross or ambulance corps can tell you where to learn this life-saving technique.

If weight loss, coughing or choking become a constant problem for the person with HD, a feeding tube may be the best way to ensure adequate and safe food intake. It is important to discuss this before it becomes absolutely

necessary, so that everyone involved understands the reasons for the change. Tube feeding does not prevent eating for pleasure, it merely ensures that the person with HD receives adequate nutrition. Nor is a feeding tube always a permanent solution. It can be used to help manage an eating, hydration or weight loss crisis until the person with HD is stable and able to again eat by mouth. The goal of all HD management strategies is to increase the quality of life for the person facing HD.



About the author – Jeann Thomson, M.S., CCC-SLP Speech Pathologist at the HD Center of Excellence at Colu Health Sciences/NYS Psychic Institute and Supervisor of St Pathology at Columbia Presb Center of New York Presbyte Hospital in NYC.