

As Huntington disease (HD) progresses in a person, eating and swallowing can become increasingly difficult. This is a common symptom in HD. Simply stated, the involuntary movements and decreased muscular control caused by HD affect both the coordination and timing of the swallowing function.

In addition to the challenges with eating and swallowing, an increased need for calories to maintain weight is common for persons with HD. Instead of the traditional 2000-2500 kcal per day required for weight maintenance, people with HD may require 5000 or more kcal per day. This means that persons who potentially require twice as many calories and are experiencing increasing difficulty with being able to consume those calories, because of eating and swallowing challenges, will probably be very hungry at times. Being very hungry may lead to responsive or challenging behaviours being displayed. These factors all contribute to the need for support and accurate information from a multi-disciplinary team who can help with these issues.

We may not realize it, but swallowing is a very complex activity. It involves coordinating the opening and closing of the mouth and lips and chewing while inhaling and exhaling. Food needs to be mixed with saliva, moved to the back of the tongue, and sent on its way down the esophagus by the swallow reflex.

Dysphagia

Dysphagia means difficulty swallowing. All of the phases of swallowing are important. Difficulty in any of the phases can affect one's ability to swallow properly. With dysphagia, it takes more time and effort to move food or liquid from the mouth to the stomach.

Preventing problems associated with dysphagia in HD is an ongoing challenge for caregivers. Placing too much food into the mouth, gulping liquids, involuntary gulping of air while breathing and difficulties with biting, chewing, and moving the food to the esophagus can increase the likelihood of aspiration pneumonia. Fear of choking during a meal can result in responsive behaviours and weight loss over time.

There are warning signs of dysphagia that may signal a need for a change in diet or the use of other strategies.

Consult a medical professional on the team if you observe these signs:

- Coughing during a meal (seek immediate assessment)
- Repeated throat clearing
- Drooling
- "Gurgly" voice
- Delay in swallow
- Multiple swallows
- Holding food in mouth
- Residue in mouth post meal
- Weight loss
- Episodes of reflux/vomit
- Complaints of dry mouth

Strategies to Cope With Dysphagia

Assessment by a Speech Language Pathologist will help to determine:

- Upright positioning
- Feeding techniques (i.e. use of straws, verbal cue when to swallow)
- Diet consistency and temperature
- Oral Care
- Frequency and duration of meal times

Strategies to Increase Calories

Consult a professional such as a Speech Language Pathologist or registered dietitian on suitable foods, textures and consistency, and tips for maximizing caloric intake.

All of the following team members can be consulted to assist in the proper care to minimize risk associated with swallowing difficulties:

- Individual
- Caregiver(s)
- Speech Language Pathologist
- Occupational Therapist
- Physiotherapist
- Dietitian
- Nursing Staff
- Social Worker
- Family Services Team
- Physician
- Neurologist
- Dentist

Tips for Caregivers

- Ensure awareness by all caregivers of swallowing difficulties.
- Minimize distractions while eating (i.e. no talking and no TV when eating).
- Encourage a slow, relaxed eating style.
- Proper positioning of individual during and after meals is important.
- Evaluate and monitor food consistencies.
- Thickening of liquids is very important to reduce risk.
- Coughing should be encouraged to clear the airway.
- Check mouth after eating for residue and clear it.
- Use special feeding equipment (adaptive utensils) as recommended by the professional team.
- Maintain independent eating skills for as long as possible.
- Use meal supplements to increase caloric intake and maintain adequate nutrition.
- Individuals with swallowing problems need to have their temperature and lung sounds monitored regularly by a medical professional for signs of pneumonia.
- Get CPR/First Aid training.

RESOURCES

Ongoing support, education and information is available from the Huntington Society of Canada (HSC). You can find a listing of our Family Services team members at www.huntingtonsociety.ca/family-services-team.

[A Physician's Guide to the Management of Huntington Disease](#)

[Understanding Behaviour in Huntington Disease: A Guide for Professionals](#)

[A Caregiver's Handbook for Advanced-Stage Huntington Disease](#)

Fact sheets on a variety of other topics including Cognitive Changes in HD, Have you Met HD?, Responsive Behaviours, Tips When Working with Individuals with HD are available at www.hdfactsheets.ca.