EATING AND SWALLOWING WITH HUNTINGTON DISEASE (HD)

As Huntington disease (HD) progresses, eating and swallowing can become more difficult. Changes in movement, muscle control, and coordination can affect how safely and comfortably a person eats and drinks. At the same time, people with HD often need more calories to maintain weight, which can add to frustration and hunger. This factsheet is designed to help individuals with HD, families, and caregivers understand swallowing challenges and learn ways to support nutrition, safety, and quality of life.

Eating and Swallowing Become Difficult:

Swallowing is a complex process that involves coordination, timing, and strength between the mouth, throat, breathing, and muscles.

- Food must be chewed and mixed with saliva
- The tongue moves food to the back of the mouth
- The swallow mechanism sends food down the esophagus
- Breathing must pause briefly to protect the airway

HD can disrupt the timing and coordination of these steps, making swallowing slower and less safe.

What Is Dysphagia?

Dysphagia means difficulty swallowing, and it can affect one or more stages of the swallowing process.

- Swallowing may take more time and effort
- Food or liquid may not move smoothly from mouth to stomach
- The risk of choking or food entering the lungs can increase

Preventing problems related to dysphagia is an ongoing challenge and requires close attention and support.

Why Swallowing Difficulties Matter

Speech Language Pathologists (SLPs) are health professionals who help with:

- Speech and communication
- Swallowing and feeding concerns
- Finding ways to reduce communication barriers

These issues can increase the risk of aspiration, pneumonia, weight loss, and responsive or challenging behaviours.

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Warning Signs of Dysphagia

These signs may signal the need for changes in diet or swallowing strategies and should be discussed with a healthcare professional.

- Coughing during meals (seek immediate assessment)
- Repeated throat clearing
- Drooling
- "Gurgly" or wet-sounding voice
- Delayed swallowing
- Needing multiple swallows
- Holding food in the mouth
- Food residue left after eating
- Weight loss
- Reflux or vomiting
- Complaints of dry mouth

Assessment and Support

Assessment by a Speech-Language Pathologist (SLP) helps identify swallowing risks and appropriate supports.

An SLP may recommend:

- Proper upright positioning
- Safe feeding techniques (e.g., pacing, cues to swallow, use of straws)
- Appropriate food textures and liquid thickness
- Oral care routines (a clean mouth prevents bacteria from getting into lungs)
- Length and timing of meals

Increasing Calories Safely

Because people with HD often need much higher calorie intake, nutrition planning is essential.

- Consult an SLP or registered dietitian
- Choose foods that are safe, calorie-dense, and easy to swallow
- Use meal supplements when recommended
- Adjust textures and temperatures to improve comfort and safety
- Increase the number of meals and snacks by scheduling them often into the day

Who Can Help?

Managing swallowing difficulties requires support from a team of professionals.
The care team may include:

- The individual with HD
- Caregiver(s)
- Speech-Language Pathologist

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- Occupational Therapist
- Physiotherapist
- Dietitian
- Nursing staff
- Social Worker
- Family Services team
- Physician or Neurologist
- Dentist

Tips for Caregivers:

Caregivers play a key role in supporting safe eating and swallowing.

- Make sure all caregivers are aware of swallowing challenges
- Reduce distractions during meals (no TV or talking)
- Encourage slow, relaxed eating
- Ensure proper positioning during and after meals
- Monitor food textures and liquid thickness
- Encourage coughing to help clear the airway
- Check the mouth after meals for leftover food
- Use adaptive utensils if recommended
- Support independent eating as long as possible
- Monitor temperature and lung sounds for signs of pneumonia
- Consider CPR and First Aid training
- Keep a diary of swallowing difficulties to track areas needing help (include time of day, distractions, mood, medications etc.

Factsheet developed by the HSC Family Services team. Reviewed by Tanya Greaser, BA, BSW, Registered Social Worker and Family Services Educator, and Jasmine Cload, BA , MSc, RSLP, S L P (C), Certified and Registered Speech Language Pathologist.

RESOURCES

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at hdsupport.ca

If you are ready to receive individual or group support from the Huntington Society of Canada, you can self-refer here: http://contactme.cloud/form/huntingtonsociety

Informational fact sheets for family and friends impacted by HD are available to view, print and download at hdfactsheets.ca

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at hdresources.ca

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