

Feeding Tube Facts for HD

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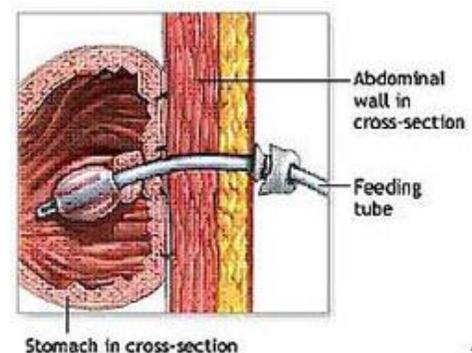
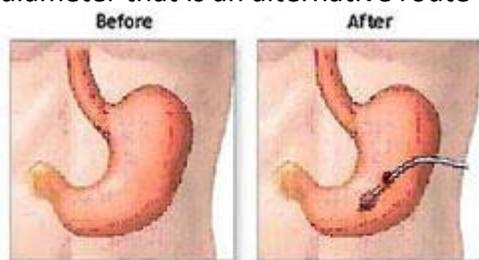
Patients in the later stages of Huntington's often have significant difficulty with swallow function and weight loss. Some patients choose to have a feeding tube placed to avoid choking, help provide adequate nutrition and fluids and take medications. Some patients experience improvement in their quality of life once a feeding tube is placed and after they gain weight, have adequate hydration and no longer struggle with choking. Feeding tubes do not need to be permanent; they can be removed when continued nutrition is no longer a goal of care such as near the end of life, and sometimes earlier if preferred.

The decision to have a feeding tube is very personal and should be discussed with your family and your HD care team. We advise that patients and families discuss this intervention early in the disease process when they have the thinking capacity to express their wishes.

Below is information about feeding tubes that may be useful as you and your family members consider your treatment preferences. Please note that preferences can change over the course of time, and the decision for or against a feeding tube can be re-visited.

What is a feeding tube?

- It is a small, flexible tube inserted through the skin into the stomach, about ¼" in diameter that is an alternative route for nourishment and hydration.



When should I consider getting a feeding tube?

- Noticeable weight loss, malnutrition, and dehydration
- Swallowing difficulties prevent eating and drinking
- Frequent choking
- When aspiration (food or liquid going down into the lungs) is suspected. Patients who aspirate are at a higher risk for pneumonia.

What are the advantages of getting a feeding tube?

- Maintain adequate fluids and nutrition
- Decrease choking
- Decrease the risk of aspiration of fluids or foods into the lungs
- Help maintain weight, reduce fatigue and improve resistance to infection
- Reduce excessive time for feeding
- Administer medications safely

What are some reasons people don't want a feeding tube?

- Insertion of a tube is a surgical procedure and may require replacement in the future.
- Fear of potential side effects:
 - A small risk of infection at the tube site.
 - Temporary pain or discomfort at site of insertion.
 - The tube can become plugged or dislodged.
 - It does not prevent the progression of HD.

How will I know if a feeding tube is right for me?

- Meals are a struggle (choking, gagging)
- You spend a lot of time trying to eat enough food and drink enough liquids
- You are underweight or dehydrated
- Talk with your HD care team and family members about a feeding tube to determine if a feeding tube is right for you. You may decide you do not want a feeding tube.

When is the right time to have a feeding tube placed?

- Typically in the later stages of HD progression for those who are experiencing significant weight loss.
- Usually before you absolutely need one and while you can safely undergo anesthesia.
- When oral intake is no longer adequate to maintain fluids, weight, and satisfy hunger.

Are there signs that I'm not getting enough fluids?

- Dry mouth, elevated heart rate, dark urine or very small amounts of urine
- If you cannot consume six to eight ounce glasses of water or non-caffeinated beverages per day
- Note: Foods that are liquids at room temperature, such as sherbet, gelatin and ice cream can contribute to daily fluids. Always have fluids available.

Can the feeding tube be removed?

- The feeding tube can be removed at any time.
- The tube is removed by a healthcare provider and the skin usually closes up in time.
- The tubes are designed to have easy removal and replacement when needed.

Can I still eat with a feeding tube? Yes and here's what you need to know:

- Having a feeding tube provides an alternate access to deliver nutrients, fluids and medications.
- The feeding tube can be used as the sole method of nutrition, but many patients may still be able to eat for comfort and enjoyment.
- HD Care Team, speech pathologist and nutritionist can recommend foods you can safely eat.

Can I take medications through the tube? Yes, these are your options:

- Medications available in liquid form can be easily given through the tube.
- Medications in pill form can be crushed, dissolved in water and given through the feeding tube.
- Your doctor and pharmacist can verify which medications can be crushed, dissolved or are available as liquid.
- Time-released and enteric-coated medications cannot be crushed and sent down the tube; substitute medications that can be crushed are usually available.
- Always consult your HD care team OR pharmacist if you have questions about giving medications through a feeding tube.

What is the recovery from tube placement like?

- Recovery from sedation is usually within hours. The tube may be used for feedings within a day or two as per physician or discharge instructions.
- An overnight stay is generally required.
- We recommend feeding tube placement at UC Davis where we are familiar with caring for complex patients, but patients who live a great distance may undergo feeding tube placement at their local health care facility.
- Home health nursing will be ordered to provide education and to evaluate the tube site once you return home.
- Formula and needed equipment will be ordered by your doctor and delivered to your home from a medical supply provider.

What formula is used?

- Specific feeding formulas will be recommended by the Registered Dietitian and by your physician.
- Note: HD patients require more calories to maintain weight than the average person.

How are feedings administered?

- Bolus – formula is administered through a large syringe into the tube in a time period tolerated by the patient.
- Gravity feed – formula is placed in a feeding bag, put on a pole or hook 2-3 feet above you and the formula is then allowed to flow gradually through the tube for at least 30-minutes per feeding
- Continuous feed – A pump delivers a constant amount of formula throughout the day or night. Portable pumps are available.
- You must remain upright or 45-degree angle while the formula is being given and remain this way for at least an hour after the feeding finishes. If using a continuous pump feeding, you will be required to remain at the 45-degree angle.

Adapted with permission from Theresa Imperato, RN from The ALS Association of Greater New York Chapter and Certified Center at Stony Brook. The UC Davis HDSA Center of Excellence thanks and acknowledges Theresa Imperato, RN and Lorraine Danowski, RD, from The ALS Association Greater New York Chapter and Certified Center at Stony Brook for this factsheet. HD specific information developed by Kathryn Casey RN, FNP-C at the HDSA Center of Excellence at UC Davis Health. Drawings by A.D.A.M.