

Feeding Tube Facts for HD

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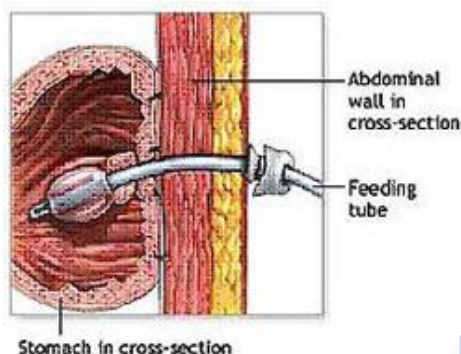
In the later stages of Huntington's some can have significant difficulty with swallow function and weight loss. Some choose to have a feeding tube placed to avoid choking, help provide adequate nutrition and fluids and take medications. The decision to have a feeding tube is very personal and should 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 ability to understand the advantages and disadvantages to feeding tubes.

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.

Let's explore some of the what, when, who regarding feeding tubes. Remember, decisions may change as the disease progresses, therefore its most important to discuss your feelings, concerns and questions with your support team and medical care team.

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 to consider:

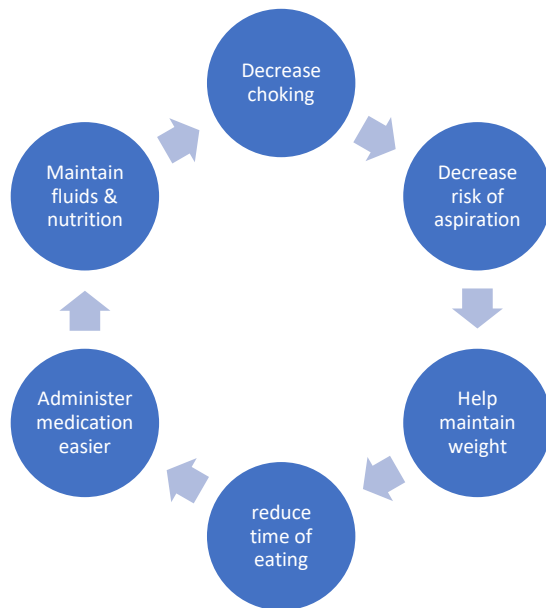
Noticeable weight loss, malnutrition, and frequent dehydration that cause concern or discomfort

Swallowing difficulties preventing adequate eating and drinking to maintain health

When food or liquid going down into the lungs, (aspiration) is suspected. Aspiration can put persons at higher risk for pneumonia

Meals are a struggle or frequent choking or gagging; no desire or energy to eat any longer

Feeding Tubes-- Advantages vs. Disadvantages



- May require replacement in the future, another procedure
- Small risk of infection at tube site

Surgical Procedure

- Tube can get plugged or dislodged
- Can be easily pulled out
- Caregiving needed for cleaning, feedings and maintenance

Potential Side Effects

Frequently Asked Questions – Discuss all questions & concerns with your medical team.

Can feeding tube be removed?

Yes

Would be a medical procedure, speak with your medical team to discuss options

Can you still eat with a feeding tube

Yes

Many people will still eat some food for comfort or pleasure as the feeding tube is utilized to maintain proper nutrition to maintain health and life

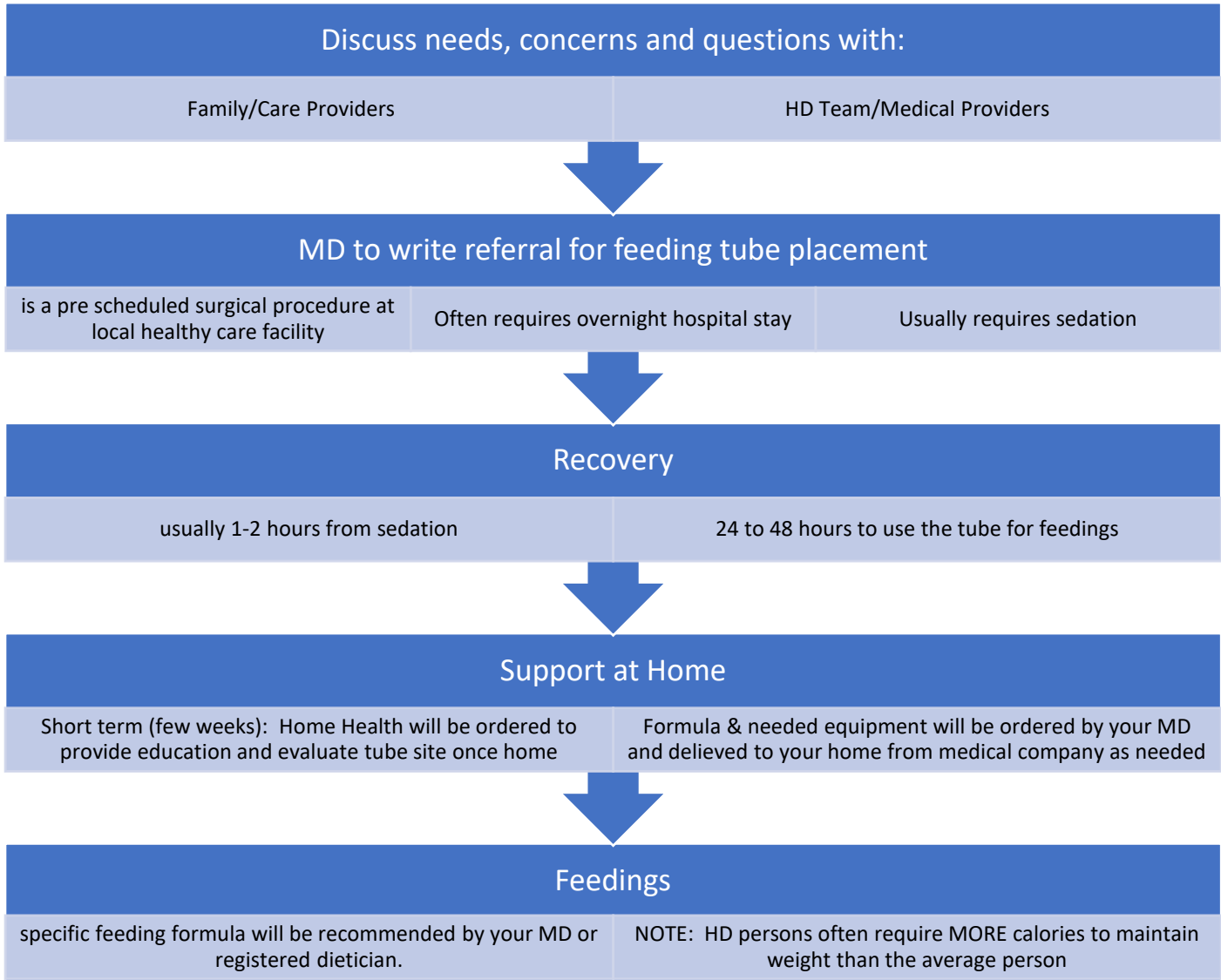
Can I get medications through the feeding tube?

Yes

Medications can be administered through the tube in liquid form, crushed & dissolved in water



Feeding Tube Process



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. Drawings by A.D.A.M.



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