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## Feeding Tubes

### **Introduction**

A change in the patterns and abilities of individuals with Huntington disease is not uncommon. As swallowing becomes increasingly impaired, eating by mouth compromises adequate nutrition. At this point some people with HD may choose to receive their nutrition through a gastrostomy tube. Although it is a relatively minor surgical procedure, placement of a feeding tube has greater implications than simply enhancing nutrition. Deciding whether or not to have a feeding tube forces the individual and his family to confront difficult emotional or spiritual issues about extending life, the quality of life, and providing basic sustenance to prevent starvation. These are very personal decisions, and your understanding and support are needed.

### **What are feeding tubes?**

Placement of a gastrostomy tube (commonly called a “g-tube”), a peri-epigastric tube (commonly called a “PEG”), or a jejunostomy tube (commonly called a “j-tube”) may not mean that it is no longer possible to eat by mouth. It is often good practice to continue to take some favourite foods orally. Remember, too, that placement of a feeding tube can be a short-term intervention to help build body weight so that the individual can resume eating primarily by mouth.

For detailed information about feeding tubes you will need to speak with an appropriate professional, family doctor, dietician, or speech language therapist.

### **What do I need to know about feeding tubes?**

If an individual has a feeding tube, the spot where the tube is placed is particularly prone to infection. Look at this area closely whenever you feed or provide personal care. It is important to pay close attention to washing, rinsing, and drying the skin around

the tube when you assisting with bathing. Remember to wash your own hands. Follow any special instructions you may be given to keep the tube and the area around it clean. Be sure to report any signs of infection to your family doctor or supervisory nurse so they may be assessed.

Be sure the individual is always positioned so that their head is above the level of the stomach to prevent regurgitation or aspiration. Positioning is particularly important while the tube feed is running; in situations when appropriate positions are not optimal there is a risk of reflux. The best position for enteral feeds is 60-degree hip flexion during and for an hour after the feed for boluses, or reclined not less than 30 degrees and 60 or higher as much of the day as possible.

People with severe chorea may find that the area around the tube becomes sore or tender from the repeated involuntary movements of the arms and legs touching or pushing against the area around the tube. Some may find the site so irritating that they tug at the tube, which loosens it. They may injure themselves or even remove the tube. To protect them from accidentally irritating the area or to prevent having to replace the tube, a doctor may order a binder to wear over the site. It’s important to put the binder on correctly. If the binder does not fit snugly and smoothly, it will further irritate the skin rather than soothe the discomfort.

### **When Considering a Feeding Tube**

Many people with HD and their families struggle with the decision of whether or not to use a feeding tube. It is never an easy decision, and it is best made well in advance of a crisis. Here are some considerations about feeding tubes. A feeding tube may be called for if:

- There is a nutritional crisis

- There is a hydration crisis.
- There is repeated aspiration pneumonia.
- There is a severe swallowing problem.
- There is great fear of choking or aspirating.
- It makes continuing an active life easier.
- There are other conditions, disorders, or complications.

Placement of a feeding tube may be appropriate if previous attempts at continuing to eat by mouth have included:

- Changes in position.
- Changes in the consistency of the food.
- A speech therapist's swallowing evaluation.

Placement of a feeding tube may be appropriate after the following interventions have been tried without success:

- Medication to make swallowing easier.
- Interaction between the person and those helping him to eat.
- Adjustments to the environment in which he's eating.
- Achievement of a greater degree of relaxation while eating.

In some cases placement of a feeding tube may be detrimental. The "right" decision requires that everyone involved make every effort to make their contribution as informed as possible.

*Taken from: A Caregivers Handbook for Advanced-Stage Huntington disease.*