

Huntington Disease and Feeding Tubes

As Huntington disease (HD) progresses in a person, typically there are issues with weight loss, involuntary movements, diminished coordination, and difficulty with walking, talking, eating and swallowing. To address the change in abilities of individuals with HD, the introduction of a feeding tube provides an option for individuals struggling to eat, drink and maintain their weight.

Many people with HD and their families struggle with the decision of whether or not to use a feeding tube. The 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/her family to confront difficult emotional or spiritual issues about extending length of life, the quality of life, and providing basic sustenance. These are very personal decisions which require significant discussion, understanding and support from family members.

Acknowledging and honouring the individual's wishes requires that everyone involved make their contribution as informed as possible. It is never an easy decision, and it is best made well in advance of a crisis. It is recommended that these kinds of decisions about care are discussed and written down in an Advance Care Directive or Plan*. Advance care planning is the process of having conversations, making decisions, and identifying how people would like to be cared for. An Advance Care Plan enables the person's voice to be heard (while he/she still has the ability to clearly communicate preferences for care) and gives a person's loved ones the knowledge and confidence to act – when the time comes - without guilt or worry. The Advance Care Directive can be made available to family members, the medical team, as well as the long term care facility and caregivers – to refer to when needed.

WHAT ARE FEEDING TUBES AND HOW DO THEY WORK?

Feeding tubes (also called gastrostomy tubes) are plastic tubes that are used to provide nutrition to people who are not able to meet their nutrition and hydration needs by mouth. There are several different types of feeding tubes that can be used. A tube is placed through a small hole in the abdominal wall – into the stomach (a relatively minor surgical procedure). This allows liquid nutrition to be given to the person.

Placement of a gastrostomy tube (commonly called a "g-tube"), a percutaneous endoscopic gastrostomy tube (commonly called a "PEG"), or a jejunostomy tube (commonly called a "j-tube") doesn't automatically mean the end of eating by mouth. Sometimes it is possible for a person with a feeding tube to still safely take certain foods orally to allow the pleasure of tasting foods. However this should only be done in consultation with medical professionals.

IMPORTANT FACTS about feeding tubes

- The spot where the tube is placed requires cleaning daily to reduce the risk of developing infection.
- 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.
- The tube may become blocked. There are strategies to unclog the tube if this happens.
- If the tube comes out, medical assistance (including possible hospitalization) is required to replace it.
- The use of feeding tubes does not completely reduce chances of aspiration pneumonia as saliva and gastric reflux can be aspirated.
- Tube feeding in the end stages of disease does not help a person to regain skills, become stronger, gain more weight or live longer.

CONSIDERATIONS regarding feeding tubes

When an individual is not getting adequate nutrition, caregivers will want to explore every option. Sometimes, there is limited information available to families who wish to make an informed decision about feeding tubes. There also may be external pressures for families to make a decision. It is important to discuss with a person before a crisis situation occurs as this helps to ensure that the person's wishes are honoured.

- Discuss options with the team of health care professionals and family before making the decision
- Consider quality of life
- Involve hospice services or a palliative care team as an alternative to feeding tubes in end stages of HD

A FEEDING TUBE may be suggested in the following cases:

- Individuals are unable to meet their nutrition or hydration needs
- There is repeated aspiration pneumonia
- There is a severe swallowing problem and changes in medication do not alleviate this problem
- There is great fear of choking or aspirating
- It makes continuing an active life easier
- There are other conditions, disorders or complications
- Following a swallowing evaluation and nutrition assessment

TIPS FOR CAREGIVERS - when feeding tubes are in place:

- Caregivers should pay close attention to washing, rinsing, and drying the skin around the tube when assisting with bathing.
- Report any signs of infection to your family doctor or supervisory nurse so they may be assessed.
- Consult the speech language pathologist or healthcare team members to determine the best positions during and after feedings.
- Ensure the individual is always positioned so that his/her head is above the level of the stomach to prevent regurgitation or aspiration during feeds and flushes.
- To reduce the risk of the tube becoming dislodged, a doctor may order an ace bandage or abdominal binder to wear over the site. Correct application of the binder is critical to prevent further irritation of the skin.

RESOURCES

For detailed information about feeding tubes, speak with a speech language pathologist, dietitian or physician.

Consult with a Huntington Society of Canada Family Services team member and the resources found at www.huntingtonsociety.ca for more information on the use of feeding tubes and other topics related to HD.

A Physician's Guide to the Management of Huntington Disease (Third Edition)
A Caregiver's Handbook for Advanced Stage Huntington Disease
HSC Fact Sheet on Eating and Swallowing

Other resources consulted in the production of this fact sheet:

*Advance Care Plan: <http://www.advancecareplanning.ca/across-canada/advance-care-plans-and-living-wills-whats-the-difference/>

Choosing Wisely Canada - Canadian Geriatrics Society (2014): *Feeding tubes for people with Alzheimer's disease*