FEEDING TUBES AND HUNTINGTON DISEASE (HD)

Huntington disease (HD) can progress to the point where meeting nutritional needs becomes a challenge. Changes in movement, swallowing, and coordination can make it hard for a person to eat or drink enough to support comfort, health, and quality of life. In these situations, some families consider a feeding tube to help maintain nutrition and hydration. This factsheet provides information that can help clarify why feeding tubes are sometimes considered and what families may want to think about when making this decision.

As HD gets worse, people may have:

- Weight loss
- Trouble walking, talking, eating, and swallowing
- Uncontrolled movements and poor coordination

A feeding tube can help people who have trouble eating or drinking enough to stay healthy.

What Is a Feeding Tube?

A feeding tube (also called a gastrostomy tube or G-tube) is:

- A soft plastic tube placed through the stomach area with minor surgery
- Used to give liquid food and fluids

Types include:

- G-tube (gastrostomy tube)
- PEG tube (percutaneous endoscopic gastrostomy)
- J-tube (jejunostomy tube)

When to Talk About a Feeding Tube

- When someone isn't getting enough food or water
- When swallowing is very difficult or unsafe
- When there's fear of choking or repeated pneumonia
- When a tube may make daily life easier
- After a swallowing and nutrition assessment

Making the Decision

Choosing a feeding tube can be a difficult and emotional choice. **It's not just about food. It's also about:**

- Quality of life
- How long someone might live
- What kind of care they want to receive

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These choices are very personal and should involve:

- Family members
- Medical staff
- Emotional or spiritual support

Planning Ahead

It's best to make decisions before there's an emergency. Talk about care wishes early and write them down in an Advance Care Plan or Advance Care Directive.

This plan helps:

- Make sure the person's wishes are respected
- Give family members clear guidance
- Reduce stress, guilt, or confusion later

Copies can be shared with:

- Family
- Doctors and nurses
- Long-term care staff and caregivers

Questions to Ask Before Deciding

- What does the person want for their quality of life?
- What are the medical pros and cons?
- What are other options, like palliative or hospice care?
- Have all family members had a chance to discuss and understand the plan?

Important Facts About Feeding Tubes

- The skin around the tube must be cleaned every day to prevent infection
- Involuntary movements (chorea) can make the area sore or tender
- The tube can sometimes get blocked. There are ways to unclog it
- If the tube comes out, see a doctor right away
- A feeding tube does not fully prevent pneumonia from aspiration (food or fluid entering the lungs)
- In late stages of HD, tube feeding does not make people stronger, gain weight, or live longer

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Tips for Caregivers

- Clean the area: Wash, rinse, and dry the skin around the tube daily
- Watch for infection: Redness, pain, or fluid should be reported to a nurse or doctor
- Check positioning: Make sure the person's head is higher than their stomach during and after feeding
- Prevent dislodging: A doctor may suggest using a soft abdominal binder or wrap to keep the tube in place
- Work with the care team: Speech language pathologists and nurses can help guide safe feeding and positioning
- People with feeding tubes can sometimes still safely eat small amounts of certain foods. Always check with a doctor or speech language pathologist before doing so

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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