

# Feeding Tubes and ALS

How a feeding tube can help improve your quality of life

Your care team believes you could benefit from a feeding tube. Deciding whether to have a feeding tube placed in your stomach is an important decision in how you manage your ALS. Review the following information and talk with your ALS care team about your goals of care to help decide if a feeding tube is right for you.

## What is the purpose of a feeding tube?

A feeding tube could improve your quality of life when you are having certain symptoms caused by your ALS. These include:

- ♦ Aspiration of food and liquids—*Aspiration* means the food or liquid goes into your airway or lungs by accident.
- ♦ Difficulty swallowing
- ♦ Difficulty maintaining your weight and energy
- ♦ Difficulty drinking enough water to stay hydrated
- ♦ Meals take a long time—for example, more than 45 minutes.

## How is a feeding tube helpful?

A feeding tube can help you get the nutrition you need to stay at a healthy weight and keep your energy. A feeding tube also can help you get the water and medications you need.

Having a feeding tube doesn't necessarily mean you won't be able to eat or drink. Some people with ALS get all their nutrition by mouth and use the feeding tube only for water and medications. Other people get some nutrition by mouth and the rest with tube feedings. Others use their feeding tube for all their nutrition, water and medication.

Your ALS team, including your doctor, speech therapist and dietitian, will help you decide what feeding plan is more likely to improve your quality of life. If you decide to have a feeding tube

placed, know that you can stop your tube feedings at any time you and your ALS care team believe that you no longer benefit from them.

## How is a feeding plan created?

Your ALS dietitian will first assess your nutrition needs. Then your dietitian will recommend an individualized feeding method and plan to meet your needs.

After your feeding tube is placed, your dietitian will call you weekly to check how your feedings are going. Once feedings are going smoothly, your dietitian will call every other week or monthly. Your dietitian:

- ♦ Will help find solutions to any problems you may be having with your tube feedings.
- ♦ May change your feeding method or plan.

## How do tube feedings work?

Different feeding methods are used with a feeding tube.

### Bolus feeding

The method used most often is *bolus feeding*. With bolus feeding, you take a bolus—or dose—of formula 3 to 4 times a day. Each bolus feeding takes 15 to 30 minutes, depending on:

- ♦ How much formula you need.
- ♦ If you are doing the bolus feeding yourself or have some help.

## Continuous feeding

Some people don't tolerate bolus feedings. A different feeding method called *continuous feeding* might work better.

Continuous feedings require using a pump to deliver the formula. The pump is small and easy to move or carry with you, so you can continue with your regular daily activities.

Typically, continuous feedings take place over a period of 10 to 24 hours per day.

## Are there different types of feeding tubes?

For people who have ALS, the most commonly placed feeding tubes are *PEG* and *RIG* tubes. The difference between the tubes is in the way they are inserted.

- ♦ **PEG** is short for percutaneous endoscopic gastrostomy.
- ♦ **RIG** is short for radiologically inserted gastrostomy.

We recommend using a RIG tube if you have breathing problems.

## How is a feeding tube placed?

Having either a PEG or RIG placed in your stomach requires a procedure at the hospital and typically an overnight stay. The short hospital stay is important for several reasons. We want to make sure that:

- ♦ You fully recover from the procedure.
- ♦ Your feeding tube is working properly.
- ♦ You can manage tube feedings with no difficulty.

During your hospital stay, you also will learn how to use and care for your feeding tube.

## How do I get my feeding tube supplies?

Whether you live at home or a skilled nursing facility, preparing and doing tube feedings is key to safely and effectively getting the nutrition, water or medication—or all 3—that you need.

### If you live at home

A professional from an infusion services company will visit you after your feeding tube is placed. The infusion company provides a month of formula and other supplies you need for your tube feedings.

If you're doing continuous feedings, the infusion company also will provide a pump and teach you how to use it.

You can call the infusion services company if you have any questions about your feeding supplies.

### If you live at a skilled nursing facility

Your facility will provide the formula and supplies for your tube and feedings. Nursing staff will help with your feedings and care of your feeding tube.

## How do I care for my feeding tube?

Your radiologist and hospital nurse will give you more information about how to care for your feeding tube.

- ♦ Washing your skin around the feeding tube with warm water and soap is part of daily care.
- ♦ Flushing your feeding tube with water before and after each feeding or medication you take also is important to prevent the tube from clogging.

Using your feeding tube at home to take formula, water or medication by yourself may feel overwhelming at first. However, you will receive step-by-step instructions to help you understand everything you need to do correctly and confidently.

You'll receive instructions before you're discharged from the hospital. An infusion nurse also is available by phone if you need help.

## What are the risks of having a feeding tube?

Some problems can occur with use of a feeding tube. The most common include a broken tube, clogged tube or leaking tube, or the tube may accidentally come out.

Some people experience a skin rash around the opening where the tube is placed.

## Does health insurance cover the costs?

Most health insurance companies provide coverage and benefits for placement of a feeding tube and for the feeding tube supplies, including formula, for people who have ALS.

However, we strongly recommend you check with your insurance company before making a decision.

## How do I decide what's best for me?

As partners with you in your health care, we provide support to help educate, encourage and empower you. If you have questions about feeding tubes not answered in this handout, please ask a member of your ALS care team.

At the HealthPartners Center for ALS, we are proud to provide patient-centered care. We listen carefully to you to understand your preferences and values to guide decisions about your care and help you decide what may be right for you.

## Phone number

- ◆ **HealthPartners Center for ALS**  
651-495-6212