



# Long-Term Tube Feeding Facts

What you should know

This guide is for those whose advanced illness is getting worse in spite of treatment. It is meant to help you decide whether you want long-term tube feeding as part of your care. Talk to your doctor or care provider about risks and benefits that apply in your case.

## **Long-term feeding helps many people live longer lives in better health.**

It might be the right choice for you if:

- You cannot swallow safely because you have throat cancer.
- Muscles in your throat are weakened by:
  - Amyotrophic lateral sclerosis (ALS, also called Lou Gehrig's disease); or
  - Any other disease that affects muscles you use to swallow.
- Your brain has been injured or damaged by disease.

## **Long-term tube feeding is not likely to help if:**

- Your swallowing problem is due to dementia that is getting worse.
- Cancer is certain to end your life within a few months.

Choosing to use long-term tube feeding can be a challenge. Take some time to think about your goals, values, and spiritual principles. You can make a better, informed choice if you:

- Ask questions of your healthcare providers.
- Talk with family and friends.
- Explore the experiences of other people who have faced the same choice.
- Speak to someone that you trust in your faith community.

It helps to decide before you are in the middle of a crisis. These questions and answers can help you make your choice.

## **What is tube feeding?**

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A gentle pump or large syringe is used to put liquid food into the body through a tube. The most common pathways are:

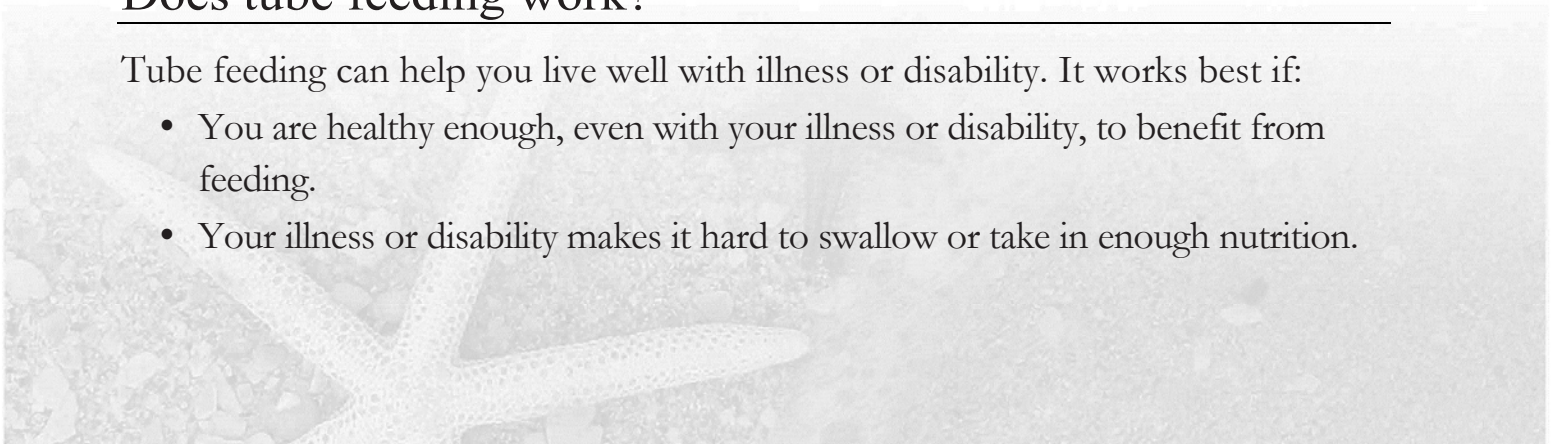
- A tube put through your nose into your stomach (for short-term use); or
- A tube put through the skin into your stomach (for long-term use).

## **Does tube feeding work?**

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Tube feeding can help you live well with illness or disability. It works best if:

- You are healthy enough, even with your illness or disability, to benefit from feeding.
- Your illness or disability makes it hard to swallow or take in enough nutrition.



Tube feeding **may NOT help** you live well if:

- Your body is failing, in spite of treatment, and death is likely in the near future.

## **Are there side effects?**

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- Liquid food given through a tube can spill over into your lungs and cause a severe infection.
- Fluids can build up if your body cannot process food and water as it should.
- This will make you feel sick to your stomach (nausea).
- Fluid build-up in your lungs, stomach, hands, and other places might cause discomfort.
- If you are confused or disorientated, your hands may need to be tied down so you don't pull out the feeding tube.

## **What could happen if I do not try a feeding tube?**

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- You may feel thirst, hunger, or nausea.
- You may feel weak, drowsy, or confused.
- Your mouth and lips may feel dry or sore.
- You may choke or get food and liquid in your lungs. A severe infection can result.

## **What should I keep in mind while I think about having a feeding tube?**

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Rest assured that you and your family will receive the education and support needed to safely manage tube feeding. In case you have other worries, here is what you can expect:

### **Will it hurt to have the tube put in?**

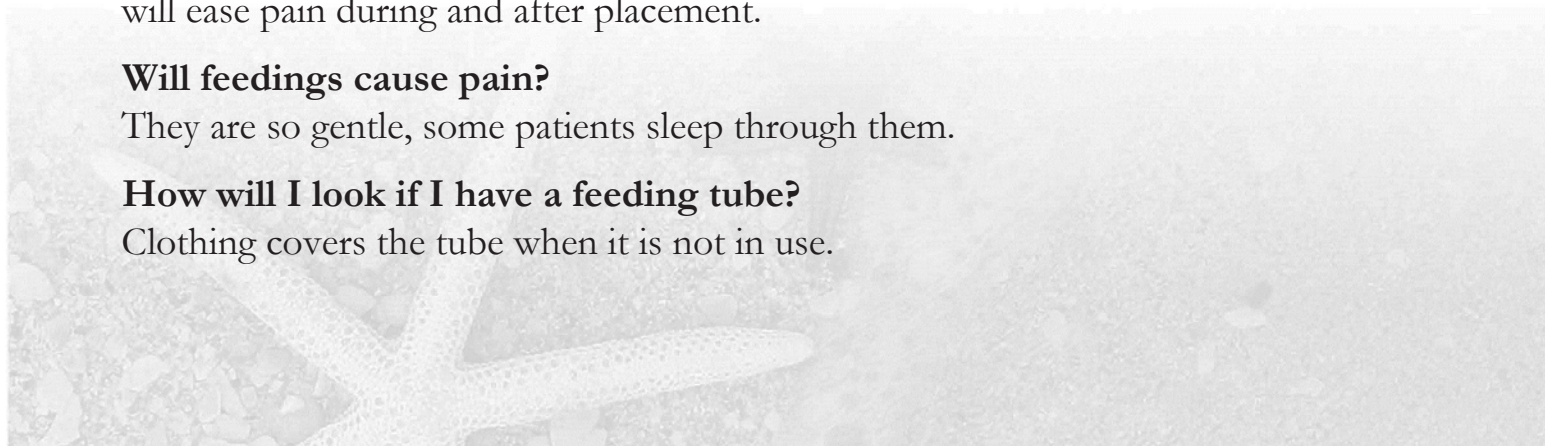
The tube is quite thin. Placement involves minor surgery in most cases. Medicine will ease pain during and after placement.

### **Will feedings cause pain?**

They are so gentle, some patients sleep through them.

### **How will I look if I have a feeding tube?**

Clothing covers the tube when it is not in use.



## Can I change my mind later?

You can always change your mind. Because you might not be able to say when to stop, talk about this with your doctor and those close to you. They need to know:

- Why you want to try the tube.
- What situations would make you want to stop tube feeding in the future.

## What if I decide not to have a feeding tube?

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You may worry about the effects of having no food or water. Talk about these fears with your doctor and loved ones. It may help to know the need for food and water becomes less and less in advanced illness.

**You will still get the care you need.** You may have a dry mouth and a sense of thirst. Proper mouth care and ice chips will be given for your comfort.

If you decide not to try a feeding tube now, you can always change your mind later.

## The choice is yours.

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Tube feeding is one of many choices you can make to live as well as you can, as long as you live. Take all the time you need to:

- Understand your options.
- Reflect on what is important to you.
- Share thoughts and concerns with your doctor and those closest to you.
- Think about who you want to speak and decide on your behalf when you are no longer capable.

Whatever you decide, plans can be made to follow your wishes.



900 Jerome Street, Suite 308  
Fort Worth, TX 76107

1-866-308-5888

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