

Facts about Tube Feeding: 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 tube feeding as part of your care. Talk to your doctor or healthcare provider about the risks and benefits that apply in your case.

Tube feedings help many people live longer lives in better health.

Tube feedings might be the right choice for you if:

- You cannot swallow safely because you have head, neck, or throat cancer.
- The muscles in your throat are weakened by a disease that affects muscles you use to swallow, such as amyotrophic lateral sclerosis, or ALS (also called Lou Gehrig's disease).
- Your brain has been injured or damaged by disease.

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 tube feeding can be a challenge. Take some time to think about your goals, values, and spiritual principles.



How do I choose?

You can make a better-informed choice if you:

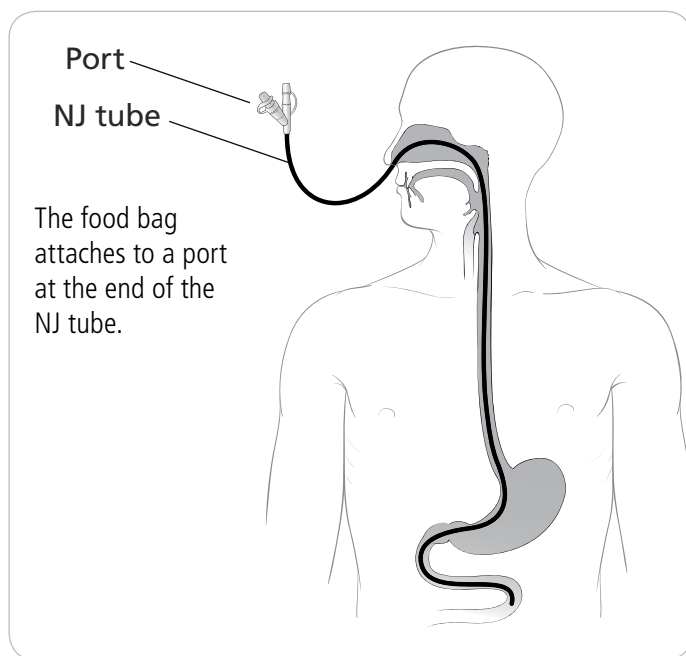
- Ask questions of your healthcare providers.
- Talk with family and friends.
- Explore the experiences of other people who have faced the same choice.
- Speak to someone who you trust in your faith community.

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?

A gentle pump or large syringe is used to put liquid food into the body through a tube. It is usually given through a tube that is put:

- Through your nose into your stomach (for short-term use), **OR**
- Through the skin into your stomach (for long-term use).



Does tube feeding work?

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.
- Your illness or disability makes it hard to swallow or take in nutrition.

Tube feeding may **NOT** help you live well if, in spite of treatment, your body is failing, and death is likely in the near future.

Are there side effects?

Some side effects to consider include:

- Liquid food given through a tube can spill over into your lungs (aspiration) and cause a severe infection (pneumonia).
- Fluids can build up in your belly if your body cannot process food and water as it should, making you feel sick to your stomach (nausea).
- Fluid build-up in your lungs, stomach, hands, and other tissues might cause discomfort.

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

- 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?

You and your family will receive the education and support needed to safely manage tube feeding. In case you have other worries, here are answers to some common questions:

- **Will it hurt to have the tube put in?** The tube is quite thin for short-term placement and does not require surgery. A long-term placement involves minor surgery in most cases. Medicine will ease pain during and after placement.
- **Will feedings cause pain?** Feedings are so gentle some patients sleep through them.

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

Clothing covers the long-term tube when it is not in use. A short-term tube is visible because it is placed in the nose.

- **Can I change my mind later?** Yes. You can always change your mind. Because you might not be able to say when to stop, it's important that you talk about this with your doctor, your healthcare agent, and those closest 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?

It may help to know the need for food and water becomes less and less in advanced illness. You may worry about the effects of having no food or water. Talk about any fears you may have with your doctor, your healthcare agent, and those closest to you. **Know that 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

Tube feeding is one of many choices to help you 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 your thoughts and concerns with your doctor, your healthcare agent, 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.

My questions

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