

LONG-TERM TUBE FEEDING FACTS

WHAT YOU SHOULD KNOW

This guide is for those whose advanced illness is getting worse despite 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.

What is tube feeding?

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 through your nose into your stomach (for short term use) known as an NG-tube.

OR

- A tube put through the skin into your stomach (long-term use) known as a PEG-tube.

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, to benefit from feeding.
- Your illness or disability makes it hard to swallow or take in enough nutrition.

Tube feeding may NOT HELP help you live well if:

- Your body is failing despite treatment and death is likely in the near future.

Long-term tube feeding helps many people live longer lives and in better health.

It may be the right choice for you if:

- You cannot swallow safely because you have a head, neck or throat cancer.
- Muscles in your throat are weakened by:
 - Amyotrophic lateral sclerosis (ALS, also called Lou Gehrig's disease)
 - 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 long-term tube feeding can be a challenge.

Take some time to think about your values, goals and beliefs. Ask your health care provider questions, talk with family and friends, and/or consult your faith community.

To speak with a certified advance care planning facilitator, **please contact us:**

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Are there long-term effects with tube feeding?

- 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, making you feel sick to your stomach (nausea).
- Fluid build-up in your lungs, stomach, hands and other places might cause discomfort.

What could happen if I do not try tube feeding?

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

What if I decide not to have a feeding tube?

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 as sense of thirst. Proper mouth care and ice chips will be given for your comfort.

What should I keep in mind while I think about having a long-term feeding tube?

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:

Q. WILL IT HURT TO HAVE THE TUBE PUT IN?

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

Q. WILL FEEDING CAUSE PAIN?

- A. No, they are gentle and many people sleep through them.

Q. CAN I CHANGE MY MIND LATER?

- A. Yes, you can always change your mind. Because you might not be able to say when to stop, talk 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.



THE CHOICE IS YOURS.

Tube feeding is one of many choices you can make to live as well as you can, as long as you live. If you decide not to try the feeding tube now, you can always change your mind later.

Take all the time you need to:

- Reflect on what is important to you.
- Share thoughts and concerns with your doctor or loved ones.
- Think about who you want to communicate on your behalf when you are no longer able to do so.
- Understand your options.

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