

Deciding About Tube Feeding

A guide for you, as a patient, or your

Substitute Decision-Maker(s)



Providing Patient and Family Centred Care

Here are some questions you may want answered before you make a decision about tube feeding:

1. What is tube feeding?
2. When is it time to think about tube feeding?
3. What are the benefits of tube feeding?
4. Does tube feeding always help?
5. Is tube feeding always possible?
6. What are some of the risks of tube feeding?
7. Will I feel hungry or thirsty without a feeding tube?
8. If I do not have tube feeding, what treatment will I have?
9. How do I make a decision about tube feeding?
10. What happens if I cannot make a decision myself?
11. Who can answer my questions and help me decide?

This guide helps to answer all of these questions. It is important to be actively involved in your healthcare. Learning about tube feeding will help you and your Substitute Decision-Maker(s) to be informed and understand the reasons to choose or not to choose tube feeding.

In this guide 'I', 'you' or the term 'patient' refers to a patient, client or resident. It is best to be able to make decisions for yourself as a patient when you can. There are times when you may not be able to make your own healthcare decisions. This book will help you and your Substitute Decision-Maker(s) learn about tube feeding and make the right decision for you and your healthcare.

1 | What is tube feeding?

Tube feeding is a way to provide nutrition (food) and hydration (fluid) to a person who has a working digestive system when he or she cannot eat or drink enough to help heal, to function, and/ or to sustain life. Tube feeding can be used for a short time or a longer time.

Short-term tube feeding

For short-term tube feeding, a thin tube is put into the nose, down the throat and into the stomach. A doctor or nurse puts the feeding tube in you at the bedside. The feeding tube stays in for a few days or weeks. The feeding tube is attached to a bag of liquid nutrition and the liquid flows into the stomach. Members of the healthcare team will recommend the best nutrition balance for your health needs.

Long-term tube feeding

For long-term tube feeding, a thin tube is put through the skin into your stomach or small bowel. This requires a relatively minor surgical procedure, and a member of your care team can discuss the details of this further with you. The feeding tube stays in until it is no longer needed. The feeding tube is attached to a bag of liquid nutrition and the liquid flows into the stomach or small bowel. Members of the healthcare team will recommend the best nutrition balance for your health needs.

2 | When is it time to think about tube feeding?

Providing food and fluids to patients is considered part of standard care. Whenever possible, you will be assisted in eating and drinking by mouth as much as you need and want. Your doctor and healthcare team may ask you to think about tube feeding when you:

- cannot swallow safely, **or**
- are not able to eat or drink enough, **and**
- need more nutrition to help you heal, to prepare you for surgery, to support you while you undergo a treatment that may help you get stronger, or to sustain your life.

It is not easy to make a decision about tube feeding. It is important to think about whether tube feeding would be helpful at this time. Members of the health team are here to help you make this decision.

3 | What are the benefits of tube feeding?

Tube feeding provides nutrition when you are not able to swallow safely or eat and drink enough calories to meet your current healthcare needs.

4 | Does tube feeding always help?

Tube feeding can be helpful for some people, depending on your specific condition and care goals. It is important to note that tube feeding does not necessarily prolong life or improve nutrition in a meaningful way. For some people, tube feeding can make their quality of life worse and be of no overall benefit. Tube feeding is generally not recommended for people with rapidly progressive or incurable illness, especially at the end of life.

5 | Is tube feeding always possible?

It may not be possible to put a tube into the nose, throat, and stomach if there is injury or obstruction to these areas or in another area of the digestive system. Putting a tube into the stomach is not done if it is difficult to enter the stomach safely.

6 | What are some of the risks of tube feeding?

There are some risks of tube feeding to think about:

- fluids from the stomach may move into your lungs and cause pneumonia
- you may have looser bowel movements
- you may have red, irritated or infected skin in the area where the tube was inserted
- you may experience discomfort in your nose, throat, or stomach from the tube
- you may need to wear restraints, following a discussion with your Substitute Decision-Maker(s), if you become confused and try to pull out the tube
- you may develop an infection or bleeding in the area that the abdominal feeding tube is inserted, or you may develop an infection inside your abdomen

Complications are more likely to occur in people who are elderly or have a number of health problems. Members of your healthcare team are aware of these risks. Your doctor or nurse will discuss them before putting in a feeding tube and your healthcare team will try to lessen/ alleviate them during your daily care. Your health team assesses your care daily and will try to address any problems that may develop.

7 | Will I feel hungry or thirsty without a feeding tube?

You may feel hungry or thirsty if you are unable to eat or drink due to injury, surgery, or obstruction. However, when you are very ill, or in the later stages of a life limiting illness, it is common **not** to feel hungry or thirsty. Often, near the end of life, people gradually reduce the amount of food and fluids they take, or may not want anything to eat or drink at all.

8 | If I do not have tube feeding, what treatment will I have?

You will always receive the most compassionate care. Particular attention will be paid to your comfort and to maintaining as much function as possible. This may include:

- helping you eat and drink whatever you are able
- oral care to keep your mouth clean and moist
- pain and symptom control

9 | How do I make a decision about tube feeding?

Each person and situation is different. You need to make a decision that is right for you:

- Think about why tube feeding is being considered and whether it can help you achieve your healthcare goals.

- Think about the benefits and risks of tube feeding with respect to your physical and emotional health; your personal values, beliefs and wishes; and as part of your particular cultural and religious system.
- It is legally, ethically and morally acceptable for you not to use tube feeding. When tube feeding does not meet your needs or when its burdens and disadvantages are greater than its benefits, then tube feeding does not need to be started or it may be stopped.
- It is best for a person to make his or her own decision about tube feeding when able to do so. However, it does not mean that you should make the decision alone. It may help to speak with your healthcare team, your family, close friends, family doctor, bioethicist or clergy.

10 | What happens if I cannot make a decision myself?

- When you are not able to make a decision for yourself, your Substitute Decision-Maker(s) makes the decision for you based on your known wishes and preferences. It is best to talk to your Substitute Decision-Maker(s) about your wishes about healthcare in advance. Your wishes can be written or spoken and must be respected.
- When your wishes are not known, your Substitute Decision-Maker(s) must think about your values and beliefs and what you would likely have wanted if you were able to make your own decision.

11 | Who can answer my questions and help me decide?

You can talk to any member of your healthcare team about any questions or concerns you have about tube feeding. Members of your healthcare team include:

- Doctors
- Nurses
- Dietitians
- Speech-language pathologists
- Spiritual care providers
- Social workers
- Bioethicist
- Psychologist





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*This guide provides general information about the current law in this subject area. However, legal information is not the same as legal advice, where legal advice is the application of law to an individual's specific circumstances. Although we have tried to make sure that the information in this guide is accurate and useful, we recommend that you consult a lawyer if you want professional legal advice in this subject area that is appropriate to your particular situation.