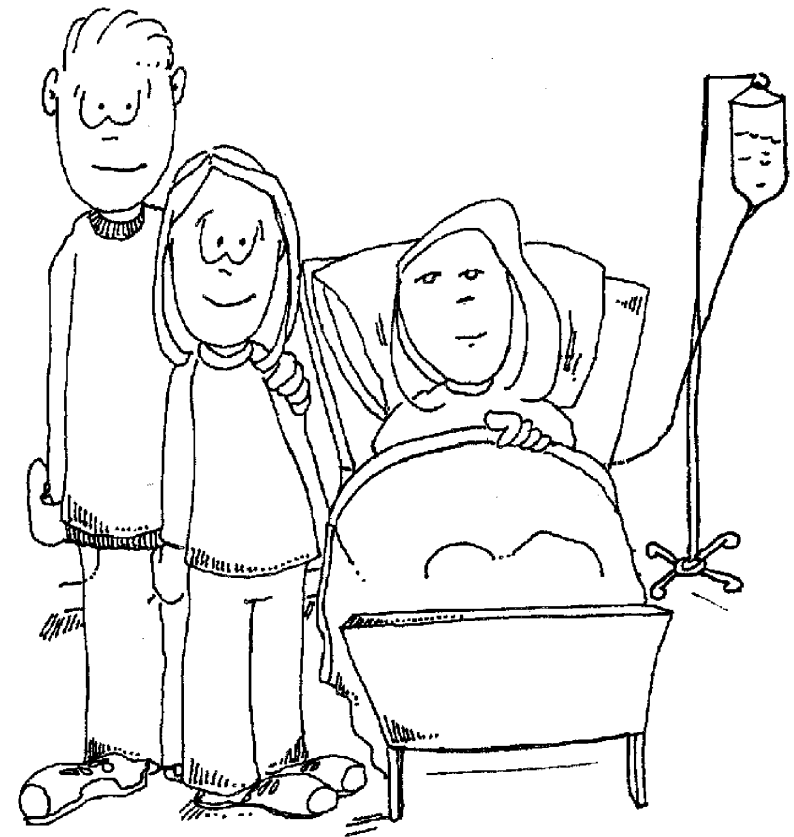

Deciding about Tube Feeding

A guide for patients, family and friends
faced with difficult choices.

For more information about this book contact:

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Notes:

What this book is about . . .

Tube feeding is a common type of life support in Canada. Some other types of life support are cardiopulmonary resuscitation or CPR, kidney dialysis, intravenous fluid, medication, oxygen and breathing machines or ventilators.

Tube feeding is used when a person cannot eat and drink enough to stay alive or when it is not safe for the person to swallow food or liquids. Tube feeding can keep a person alive for days, months or years. But, people can die even when life supports are used. The heart, brain, liver or lungs can still fail and lead to death even with tube feeding or other life support.

There are many reasons why a person may not be able to eat or drink. Sometimes, it is due to a medical or surgical problem. Sometimes, it is because death may be near.

Decisions about tube feeding need to be made carefully. We respect the dignity of each person. This means that we will usually provide tube feeding if it is needed. However if tube feeding will not benefit or will be too heavy a burden for the person receiving care, we try to do what is best for the person.

This book offers some help for persons receiving care and family and friends who are making decisions about tube feeding.



What is tube feeding?

Tube feeding is a way of giving food and fluids through a tube.

The common types of tubes are:

- **A nasogastric tube (NG tube)** is a thin, plastic tube that goes through the nose, down the throat and into the stomach. This tube is put in at the bedside. This tube is generally used as a temporary measure.
- **A gastrostomy tube (PEG tube)** is a thin, plastic tube that goes into the stomach through the skin at the stomach level. This tube is put in during a short operation.

Other ways of delivering food or fluids may be used in certain circumstances. The doctor and other members of the health care team will suggest the best way of giving food and fluids.

When do people need tube feeding?

Some people need tube feeding because:

- they have trouble swallowing
- swallowing is not safe for medical reasons
- they had a certain surgery that prevents swallowing
- they are on a breathing machine and cannot eat or drink
- they are not able to eat enough calories

This book has been prepared by members of the Education Task Force on Nutrition and Hydration Guidelines and has been revised by members of that group and by others of St. Joseph's Healthcare Hamilton including:

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This book owes much of its content to the publication:

“Patient and Family Guidelines: Making Decisions about Long-Term Tube Feeding”

The Bioethics Project
Edmonton, Alberta
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Permission was given to adapt.

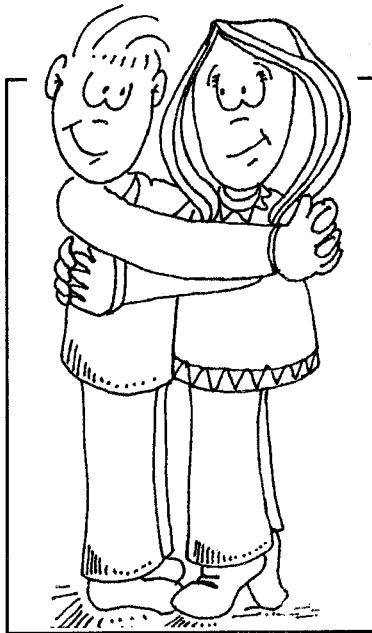
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Often, when family and friends are faced with this type of discussion about a loved one, it helps them begin to talk about what they want themselves if they are ever in the same situation. Talking about these things in calmer times is a lot easier than in times of crisis. Planning ahead can help relieve sadness, stress and guilt for everyone you love.

Is there anyone I can talk to about making this kind of decision?

Difficult choices are best made through open discussion among all those involved. Besides your doctor and nurse or family and friends, you may want to speak with the chaplain, social worker, dietitian, speech-language pathologist or ethics consultant. Your doctor or nurse can help you contact any of these people to help you make a decision about tube feeding.



This book has some questions and answers that may help you decide if tube feeding should be started or continued for yourself or someone you love. You may read this book to help you think about the kind of treatment you want if you are ever in the same situation.

Why do people start tube feeding?

Tube feeding can be started for many good reasons:

- to help build up strength if the person is not able to have enough by mouth
- to give nutrition when a person cannot safely swallow
- to provide improved nutrition over intravenous fluids alone
- to keep a person alive long enough to see if he or she can recover from a trauma or illness
- to honour a request by a person when he or she was able to decide and asked for it

Even when someone is dying, tube feeding may help by giving improved physical health, mental health and quality of life.

When a person is not conscious or mentally able, tube feeding can be started to give family some time to make a decision they feel is right.

Are there any problems with tube feeding?

Some people may have physical problems from tube feeding such as:

- fluids from the stomach coming up into the lungs causing a type of pneumonia
- looser bowel movements
- skin irritation around the feeding tube
- increased fluids making it harder to breathe

All of these physical problems will be closely watched and treated if they occur.

Tube feeding may feel uncomfortable. Nasogastric tubes may cause a feeling of choking. Some people need to be restrained or given sedation to stop them from pulling out the tube.

Some people do not want to be seen as sick and helpless around their friends and family. Others feel tube feeding prolongs their suffering while they are dying.

Does a person without tube feeding feel hungry and thirsty?

Tube feeding is sometimes started because we fear a person may starve. But, not being able to eat may be nature's way of letting someone die. That is what usually happens when people die at home or in a hospice. It has

- When a person is not able to make his or her own decision, substitute decision makers should try to make a choice about tube feeding that honours the wishes of the person. Family or other substitute decision makers should follow the person's wishes or do what is best for the person if his or her wishes are not known.
 - Stopping or not starting tube feeding should never be done to hasten a person's death.
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A Living Will or Spoken Desire

A **Living Will** describes what life supports a person wants or does not want if anything happens to him or her. It is also called an **Advance Directive**. A person who makes a **Living Will** needs to tell family and friends that he or she has one so it can be taken into account during the decision meetings. In most cases, a written **Living Will** should be followed by the family, friends and members of the health care team.

Spoken desire is when a person has told his or her family and friends what life supports he or she wants. This should be respected in the decision meetings. **Spoken desire** is important when the family talks about what the person would have wanted. Spoken desire can make it easier for members of the family to accept the plan of care.



Remember.....

People will always be treated with respect. They will be kept safe and comfortable by members of the health care team whether they are receiving tube feeding or not.

Are there any guidelines to help make a decision?

When there is a question of whether tube feeding is the right thing to do, decisions are guided by the following ethical principles:

- Giving oral food and fluid is part of the normal care offered to persons receiving care. It is not withheld or withdrawn unless it offers no benefit or is too heavy a burden to the person.
- It is morally all right for a person to refuse tube feeding when it is of no benefit or the treatment does more harm than good.
- When faced with a difficult choice like refusing life support treatment, the person receiving care is the first decision-maker. The person may want or need help from family, close friends and members of the health care team.
- Decisions about life support treatments such as tube feeding are made by looking at the benefits and burdens to each person. It takes into account the person's past and present wishes, physical and emotional condition, culture, religion, personal values and beliefs.

never been shown that dying persons are more comfortable with foods or fluids given by tube. A dry mouth can be relieved with ice chips or by moistening the mouth with a damp swab.

Making a decision about tube feeding . . .

Making a decision about tube feeding is not easy. Every person and situation is different. It is very hard to watch someone you love die. Canada does not have any law that states tube feeding must be started for someone who is dying.

In the United States, courts have decided that a person has a right to refuse or stop tube feeding because it is a medical treatment.

This topic is talked about by many religious groups. Some groups have made some decisions about tube feeding, some have not. Most groups agree that:

- tube feeding should be used when it benefits a person
- tube feeding should not be used if it is felt to be more of a burden than a benefit

The Catholic Bishops of Canada and the United States agree that when the burdens of tube feeding are more than the benefits, then tube feeding should be stopped or not started.

This means that the person receiving care, the family or substitute decision maker, with members of the health care team, make decisions for each person depending on the situation and the values of that person.

How are decisions to start, continue, or stop tube feeding made?

Life support decisions about tube feeding and other treatments can be made at any time. It is better to make decisions early. It is harder to make a decision when there is a crisis.

Tube feeding does not have to be started if it is not likely to help the person. Tube feeding can also be stopped if it is not helping or is too uncomfortable. You will need to review your feelings and decisions during the time the person is having tube feeding.

Tube feeding is not usually recommended when a person is:

- permanently unconscious
- terminally ill and near death
- near death
- not wanting to be tube fed, for any reason

A person can live for many days without food. Some fluids can be given by a tube in a vein or under the skin. This provides a small amount of nutrition. Some people on tube feeding can eat and drink if they are able to swallow safely.

Some people accept a certain amount of risk of choking or getting pneumonia that may result from food or fluids going into the lungs.

Decisions around tube feeding should always be made by people agreeing on the goals of treatment. For example, a decision might be made to have a trial of tube feeding to see if a person is able to recover.

When you want tube feeding.....

After a person begins tube feeding, you and members of the health care team will meet to decide **whether to keep on feeding or stop**. These meetings will be arranged regularly, depending on each person's medical condition and plan of care. The family or members of the health care team can request a meeting anytime they want to talk about changing the plan.

