

A CONVERSATION ABOUT TUBE FEEDING

a guide for clients, families and friends
healthcare professional guide



Health Care Professional Guide Pamphlet Information

If you are reading this booklet, you or someone you care about is having problems with eating and drinking. There are several ways to address this problem:

- careful intake by mouth
- tube feeding
- intake by mouth and tube feeding

Healthcare Professional Guide

All team members have a role in hearing client concerns and addressing/forwarding concerns in the interest of provision of best care. While content will obviously be tailored to client's needs, the points below are intended to be reminders of discussion that may be pertinent and some dialogue. Tube feeding is not a simply a technical issue, there are other factors that need to be considered. Remember to elicit concerns clients, family and caregivers have during the course of the discussion.

Introduction:

This booklet will focus on tube feeding. Tube feeding is one of the ways used when a person cannot eat or drink enough for their body's daily needs or when some people think is not safe for someone to swallow food or liquids by mouth. This booklet is a starting place for conversations about tube feeding and is intended to offer some facts that can help make these choices. Decisions to start, carry on, or stop tube feeding can be very difficult to make. Through some questions and answers, this booklet will talk about issues and concerns that have raised questions for others.

Ask your client about prior experience/ exposure to tube feeding and elicit comments/concerns about tube feeding. For Example:

1. Have you ever known anyone who has been fed by a tube?
2. What do you know about tube feeding?

There are two main types of tubes:

- A tube that is placed through the nose and into the stomach.
- A tube that is placed directly into the stomach through a small opening made during a short operation.

For both kinds of tubes, special liquid food (formula), fluids and pills in liquid form or pills crushed in water can be put through the tube.

A plan is set up based on a person's needs. At first, if people have not been eating very much at all before the tube is placed, the formula is given slowly and in small amounts.

As you become more used to the formula the amount is increased and the formula may be given more quickly.

Assess the benefit to providing a description of tube feeding administration, as well as samples of products used such as bags/tube/formula. For many individuals the concept of tube feeding is very foreign and a brief description of tube feeding and how it fits within a person's day can add clarity and understanding that makes decision-making easier.

Remember to let your client/family/caregiver know:

- Referral to a surgeon is required to determine whether a tube can be placed.
- The surgeon should describe the surgery and risks of same.

The plan is set up specially for each person but formula is often given from 3 to 5 times a day and in general it takes one half to one hour each time. Tube feeding may be given at meal or snack times.

Possible questions that may be useful to elicit any concerns clients/family may have about how tube feeding will affect their day to day life include:

- Do you have concerns about how tube feeding will fit into your daily life?
- From what I've described so far, do you have any questions or concerns?



Why do people start tube feeding?

Everyone's situation is different. Tube feeding can be used for a little while or for the rest of your life. Your health care team will discuss your situation with you so you may make the best choice.

Tube feeding may be given for a number of reasons:

- To help build up or keep your strength if you are not able to eat enough by mouth.
- To provide food and fluid if you cannot swallow safely.
- To support you in your healing from an accident or illness.
- To see if tube feeding is right for you.

It may be helpful to focus on the situation that your client is facing for which tube feeding would be recommended.

Suggested commentary which may be applicable to your client includes:

Someone may need help with feeding when they are too sick to eat or drink as they typically would. This may be from something very sudden, for example, a stroke or an accident.

For clients with chronic progressive illness such as Lou Gehrig's disease (ALS), cerebral palsy, Parkinson's disease, the following may apply:

Usually difficulty with eating increases over time and tube feeding may help.

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

At first, your health care team needs to figure out if tube feeding will work for you. If tube feeding can do what it is supposed to (e.g. the tube can be placed and your body can use the nutrients given), then you will want to think if tube feeding is desired in your situation. In some cases, if you regain strength or your ability to swallow returns, you may not need a tube feeding anymore or eating by mouth may be combined with tube feeding.

Be clear about the anticipated effect of tube feeding for your specific client and invite your client to describe what goals he/she would like from tube feeding to ensure that realistic and understood expectations are developed.

Reinforce that the purpose of the discussion is to let the client know about tube feeding so he/she and their family can work together to make the best decision. This decision is personal and individual, what is best for one person is not best for all.

As a reminder, it may be important for the

Examples of benefits may include:

- Better nutrition to gain or maintain weight if desired.
- Improved growth for children.
- More energy and alertness.
- Greater ability to fight and deal with infections.
- A way to give medications.
- Improved bowel regularity.
- Reduced burden of eating if this is hard or not a pleasure.

There are times when tube feeding is not helping or may feel like a burden:

- Certain health conditions affect how you digest your food. If this happens, tube feeding may not work. In some cases, other ways of getting food may be looked at.
- Some problems such as vomiting (throwing up), bloating or diarrhea may occur. Often these issues can be worked out with help from the health care team.
- Other problems that may occur are blocking of the tube or breaking of the tube requiring the tube to be cleared or replaced.
- Special equipment and training is needed for tube feeding. At times it may be help to have other trained caregivers on hand.
- Feeding times may get in the way of other events, though the health care team can provide ideas and change feeding times. Many clients are able to resume usual activities after the tube is placed. Talk with a member of your health care team about

Health Care Team to be aware of (unspoken) fears/concerns that client/family bring to this discussion. Common fears/concerns include:

- being fed by a tube is unnatural as it requires a medical procedure and may prolong the dying process.
- if food and fluids are not provided, the client will “starve” to death
- one may be compelled to accept tube feeding and feel they don’t have a choice
- one may feel they are not able to stop tube feeding once started
- concerns may be present about the impact of tube feeding on social life and sexual expression:
 - o sense of being “tethered” to tube feeding
 - o negative visual impact.
 - o The interference of tube feeding on intimacy and sexual expression

At end of life, research shows that it is anticipated for people to stop eating and drinking as part of the dying process and discomfort or pain is not usually seen when people stop eating and drinking. In fact, people may be more comfortable without food and fluid. A dry mouth can be relieved with ice chips, or by moistening the mouth with a damp swab or with a lubricating spray.

If tube feeding is started, can a person still eat or drink by mouth?

Some people can still eat or drink even if they are receiving some or most of their nutrition by tube feeding. The health care team will talk about your plan with you.

While tube feeding will address nutrition needs, in some cases small amounts of food and liquid may be taken for pleasure. If you are recommending no oral intake, describe the recommended plan and reason for same.

This issue may prompt some discussion of differences of opinion as to what is best.

How will this affect where a person lives?

There are many people who live in their own home while on tube feeding. While you may need to be in hospital because of other health conditions, tube feeding alone is not a reason for a person to be in hospital. The Manitoba Home Nutrition Program, a team of doctors, nurses and dietitians, helps those at home on tube feeding. Each person is unique and more discussion may be needed depending on your specific situation.

Describe the likely situation for your client to give them a picture of their expected hospital stay. Take care to provide detail that the need for hospital stay will be recommended by the health care team and may change depending on the client's needs.

Consider where this person fits in the array of services available and how their lifestyle may be impacted by tube feeding.



If tube feeding is not started does this mean the person will feel hungry, thirsty or will not be comfortable?

Often there is a fear of not being comfortable or being hungry or losing too much weight. The answer to this question depends on your situation. You can talk about this with your health care team.

It is understandable that a concern re: hunger, thirst and discomfort may be present, therefore reassure the client that this is a common concern. It's important to relate this information to the client's specific situation and medical condition.

In some situations, if someone continues to eat orally, and swallowing is difficult then eating may be too uncomfortable or energy consuming.

In other situations, if a client eats little or no food or fluid, feelings of hunger and thirst may or may not dissipate.

Provide reassurance that with or without tube feeding these experiences will be addressed.



Do people ever decide not to start tube feeding even if it is possible?

In some cases, people may find that tube feeding does not help them meet their goals. For example, a person may want to eat by mouth even if they have problems with swallowing.

While this may not apply to you, in some cases, people whose illness has advanced to its final stage, may decide to stop or not start tube feeding. At present, there are no strong facts that show people are more comfortable getting food and fluids at end of life.

Relate this area to the client's specific situation as there may be situations where the health care team may not recommend starting tube feeding.

For instance, if your client is in the final stages of life it would be important to review and anticipate common features of that stage of their illness.

One noted discomfort is dry mouth, which can be relieved with good mouth care and ice chips or sips of water.

Review and describe the dying process to your client. Recommended narrative to consider:

When people with advanced illness choose not to eat or not to accept a feeding tube they are NOT starving to death. Refusing food and water is a natural part of the dying process. When people don't eat and drink, they may become sleepier and slip into a coma. In many cases, a coma is nature's way of relieving the suffering of dying people. This may be the place to review and confirm the goal of care.



This Can be a Difficult Decision

It can be very hard to make decisions about tube feeding – whether you are making that decision for yourself or on behalf of another person.

For most of us food and mealtimes are not just about nourishing our bodies, but also about talking and being with family and friends or about showing care for others and ourselves.

It is important to allow enough time at a meeting, so that those involved in decision making have an opportunity to ask questions and to express their perspective. This may be a time when individuals talk about their fears about the client starving and possible beliefs that it is morally wrong or illegal to “let a person starve”. If the client or caregiver has expressed concerns regarding the legal, moral or philosophical/cultural obligations, this may be an appropriate time to involve other health care team members to address these issues. The client/caregiver may identify who they recognize as having this authority. Decision makers may need time to consider information and come back for an additional meeting to review information or discuss further questions and concerns.

By agreeing to tube feeding, it can feel like you are giving up the battle to fight your illness.

As well, with all those feelings weighing on you, it can seem like it might be better not to start tube feeding to avoid having to make a decision later about stopping the tube feeding.

The fear of abandoning the client may be addressed by suggesting that alternate ways may be used to “nourish” the client. Alternate way may include talking with the client, music, touch and massage.

What do I need to think about when making this decision?

Because decisions about tube feeding can be very hard to make, it may be helpful to talk with others to:

- gather as many facts as you need
- discuss the impact tube feeding will have on your life
- discuss the feelings you have about tube feeding

There are many different people who will be able to talk with you about the questions and concerns you may have such as:

- technical information (tubes, pumps, formula).
- emotional, mental and life changing impact
- values, beliefs and goals in life

This is an opportunity to explore areas of concern for decision makers. You can assist people in navigating the system by having contact information for various team members who might provide additional information or support. If it becomes apparent that there are differences amongst those involved in decision making, be prepared to advise them of how differences may be mediated.

Where there seems to be significant ambivalence, consider recommending a trail with agreed upon measures to evaluate effectiveness and agreed upon review times. Appreciate that ambivalence may occur after tube feeding has been started and ensure that clients/caregivers understand that discontinuing tube feeding may be an option.

