A CONVERSATION ABOUT TUBE FEEDING

a guide for clients, families and friends

Winnipeg Regional Health Authority
Caring for Health

Office régional de la santé de Winnipeg
À l'écoute de notre santé

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

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.

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.

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.

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.

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.

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 your situation.

Eating is often a time to share with people. One of the things to figure out is how to fit in having tube feeding and spend time with people.

Your health care team will give you support and help whether you choose tube feeding or not.

A decision to start, continue or to stop tube feeding is usually one of several health care decisions you are making at this time or will be considering in the future.

It sometimes helps to think of treatments (e.g. tube feeding, surgery, dialysis, antibiotics, etc.) as a MEANS or way to get to a certain goal. If a treatment can help you to reach your goal, it is usually seen as a benefit.

When people talk about GOALS of health care, they speak of seeking to cure their illness or to restore abilities affected by illness (i.e. rehabilitation) or to maintain their abilities or to deal with the effects of an illness even if the illness or injury itself cannot be cured (i.e. palliation).

At any given time, a person may be pursuing one or more goals with respect to health care. For example, a person living with diabetes who has a stroke may look for help to restore abilities affected by the stroke or a person with Alzheimer's disease may develop a blockage in the bowel that requires surgery to repair the problem.

Because everyone's situation is unique, a decision to start, continue or to stop tube feeding depends on the GOALS that best fit you and the MEANS (treatments) that best support your goals.

Ask your health care team to review your overall health with you. Talk to them about what you are hoping for or what's important to you. Talking about this will help you focus on how or if tube feeding is right for you.

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.

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.

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.

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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.

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.

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.

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

It is important that you have all the facts you need to help you make choices.

Ask your doctor or nurse to help you connect with the people who can help you think through all your options, questions and concerns.

APPENDIX

What is your role in decision making about tube feeding?

When people can speak for themselves, they are considered the primary health care decision maker. As the primary decision maker, the capable person has the final say about whether or not to start and/or to stop the tube feeding.

- Being the primary decision maker does not mean the person will be left alone to make this complex decision. People usually like to think about starting and/or stopping tube feeding with those people in their lives who know them best – family members, friends, spiritual advisors, etc.
- Questions about the impact tube feeding might or might not have can be answered by the members of the health care team – doctors, nurses, dietitians, speech language pathologists, chaplains, social workers and other resource people.

When people cannot speak for themselves, the health care team will look to others to assist with health care decision making. These others are sometimes referred to as substitute decision makers (SDM). The work of the SDM(s) is to faithfully represent the known wishes and/or interests of the person.

- When the SDM knows the person’s actual wishes about tube feeding, the substitute’s job is to communicate this information to the health care team. SDMs may know the person’s actual wishes because, at some time in the past, the person spoke to them directly about feeding tubes and whether or not this measure would be acceptable.
- At times, SDMs may not know the person’s actual preferences about feeding tubes. In this kind of a situation, SDMs usually will consider the person’s previous decisions and attitudes towards their healthcare. Reviewing the person’s “history” of health care decision making, helps the SDMs give directions about tube feeding in the present circumstance.
- At times, SDMs may not know the person’s actual wishes and may also have no way of knowing the person’s history of health care decision making. In this situation, the SDMs will have the task of deciding what the person’s “best interests” are considering the diagnosis (the illness) and the prognosis (what may happen in light of the illness).

While it can be difficult to decide what is in someone’s “best interests”, SDMs usually consider things such as whether or not the tube feeding will add or take away from the person’s overall comfort and well-being.

In Manitoba, the following people may act as SDMs:

- a Proxy (or proxies) named in a Health Care Directive

A Health Care Directive is a legal document in which capable persons may indicate who should speak for them if they are unable to speak for themselves (a Proxy Directive) and/or what their wishes would be if they could not speak for themselves (an Instruction Directive).

- a Court-Appointed Committee under the Mental Health Act or a SDM for personal care appointed under The Vulnerable Persons Living with a Mental Disability Act
- a Committee or a SDM for Personal Care may be an individual(s) or the Public Trustee
- others, including the person’s nearest relative and/or friends. “Nearest relative” is usually defined as the adult person identified first in the following list who is apparently mentally competent and available and willing to act on the person’s behalf:
    - spouse or common-law partner
    - son or daughter
    - father or mother
    - brother or sister
    - grandfather or grandmother
    - grandson or granddaughter

- uncle or aunt
- nephew or niece.

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