

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

### **Deciding about long-term tube feeding**

Tube feeding is a common type of life support in Canada. Tube feeding is only used when a person cannot eat and drink enough to stay alive. Tube feeding can keep a person alive for days, months, or even years. There are many reasons why a person cannot eat or drink. Sometimes it is because death may be near. Decisions about tube feeding need to be made carefully. This guide should help you make your decision.

### **What is life support?**

"Life support" means anything that keeps a person alive. People can pass away even when they have life support. Life support cannot always stop death from happening.

Life support may be used for a short time until a person no longer needs it. Life support sometimes is used for a long time, until death happens when the heart, brain, liver, or lungs fail. There are many types of life support: such as cardiopulmonary resuscitation (CPR), kidney dialysis, and ventilators (breathing machines). Even simple treatments may be life supporting -such as an intravenous drip, antibiotics, oxygen, and some surgeries.

Tube feeding has been used quite a bit in the past. People wanted to think it was just food and water. People now know tube feeding is life supporting, because it can delay a death.

### **What is long-term tube feeding?**

Tube feeding is a simple type of short-term or long-term life support. Tube feeding can become a permanent way of getting food and fluids. People have had tube feeding for as long as 37 years.

Tube feeding means that food and water are given through a tube into the stomach. Sometimes this tube is passed through the nose into the stomach (it is called a nasogastric feeding tube). This is a simple way of getting a tube in place. More often this tube is put into the stomach through a hole in the stomach wall (it is called a gastrostomy or jejunostomy feeding tube). A simple operation is needed to make this hole and put the tube in place.

Once a tube is in place, liquid food and water are given. Sometimes fluids are given every four hours, with a break in between. Sometimes fluids are given slowly, around the clock, so a person is always being fed. Canned fluids are usually used to feed a person. The canned fluids are put into a bag and attached to the feeding tube. Gravity makes the fluids go into the stomach. Sometimes a machine is used to pump the fluids into the stomach. Canned tube feeding costs \$20 to \$50 every day.

Tube feeding usually happens in hospital. Some people go home with a feeding tube. You can ask to see a feeding tube, or pictures of someone who is being tube fed.

## **Making a decision about tube feeding**

Deciding about tube feeding may be very simple or very hard. It is always difficult to see someone pass away, whether they have tube feeding or not.

Tube feeding, like all other types of life support, does not have to be started. No laws in Canada make it necessary to use tube feeding. Tube feeding is usually started after it has been decided that the patient will benefit from it. People sometimes have tube feeding started to show they love another person; but other persons do not have tube feeding started for the very same reason. Tube feeding is sometimes started because there is a fear of "starvation".

It may be best not to start tube feeding. It may be better to let nature take its course. Not eating may be nature's way of letting someone slip away. It has never been shown that dying persons are more comfortable with foods or fluids given to them by tube. Note: if a person is no longer eating and an intravenous drip is started, these fluids can increase the time it takes for a person to pass away.

Sometimes tube feeding is started and then stopped. Tube feeding should be stopped if no good is coming from it, or tube feeding is causing the patient problems, such as pain.

The following guide should help you make your decision.

### **Decision guide**

#### **A: Patient choice**

1. Patients can choose whether they want tube feeding or not. Patients can also choose whether they want other types of life support. Patients are encouraged to have their families, friends, and healthcare team help them with these decisions.

2. If patients make a decision without help, other people should be told about the decision. Decisions can also be written down, in a personal directive. Unless other people know about decisions, they can't be carried out if patients become very ill and unconscious.
3. If patients are not able to decide whether they want tube feeding or not, other people will need to make this decision. This decision is made by a legal guardian or healthcare agent, family members or friends, and the healthcare team.

A personal directive can say who should and who should not make this decision.

If patients haven't said whether they want tube feeding or not, then a decision is made for those patients. This decision should be based on what the patient would have wanted. This decision is also based on expected good or possible harm from tube feeding. What is best for the patient is the most important part of the decision.

#### **B: Possible good and harm from long-term tube feeding**

1. Tube feeding may be good for some patients. Good effects may include an improved or steady:
  - (a) physical health,
  - (b) mental health,
  - (c) quality of life.
2. Tube feeding may be harmful for some patients. Tube feeding can also be dangerous. The longer time it takes to die, and the suffering that can happen before death, is the most serious harm. Other common harms and dangers include:
  - (a) choking on the fluids,
  - (b) cramps and diarrhea from the fluids,
  - (c) irritation and infection from the feeding tube,
  - (d) being tied down or sedated to prevent the tube from being pulled out,
  - (e) being seen by others as sick and helpless.

3. Other possible harm with tube feeding decisions:
  - (a) family and friends, if they need to make a decision for someone else, feel responsible for their decision,
  - (b) families and friends may be divided over a decision they have to make for someone else,
  - (c) tube feeding can mean a person has a very long hospital stay. The costs of tube feeding and a long hospital stay are high.

### **C: How decisions to start, continue, or stop tube feeding are made**

1. Remember: tube feeding does not have to be started. Tube feeding can also be stopped any time. If tube feeding is started, a decision should be made every month or two about whether to keep it going.
2. Life support decisions can be made at any time. It is better to make decisions early. It is more difficult to make a decision when there is a crisis.
3. Tube feeding is not recommended when a person is, or will be:
  - (a) permanently unconscious,
  - (b) terminally ill and near death,
  - (c) at the end of a long life and near death,
  - (d) not wanting to be tube fed, for any reason.
4. Physical and mental examinations of a person can help make tube feeding decisions. Doctors can recommend whether there is hope of recovery or not.
5. An intravenous drip can be started if time is needed to make a decision about starting tube feeding. Tube feeding is not urgent if a person is getting water. A person can live for many days without food.
6. Temporary tube feeding, for one or two months, can be helpful if people are not sure whether tube feeding should be started.

7. Tube feeding decisions should follow what the patient has previously said they wanted or did not want. Written instructions in a personal directive should be followed.
8. If there are no written or spoken patient instructions, then it is best that a group decides what is best for the patient. The group's discussion and decision should be written in the patient's chart.

The group should include a legal guardian or health care agent, close family members, close friends, and involved doctors and nurses. Other people may also help: pastoral care workers or clergy, dietitians, social workers, ethicists or ombudsmen, and any other involved persons.

9. After a decision has been made to start, continue, or stop tube feeding, there is an emotional impact for everyone involved. Patients and others could expect to get some help during this emotional time.

### **D: Tube feeding procedure**

1. Before tube feeding is started a consent form should be signed saying that there is agreement with tube feeding.
2. It should be clear before tube feeding is started, how long tube feeding will be carried on (examples: one or two months). This should be written in the patient's chart.
3. After this trial period, and following another group discussion, then tube feeding will either be stopped or will be continued.
4. If tube feeding is continued, then every year a decision should be made about stopping or continuing tube feeding.
5. A decision to stop tube feeding can be made anytime, if there is more harm than good coming from tube feeding.
6. People can be kept comfortable if tube feeding is stopped, or if tube feeding is not started.

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