

## **Making Choices: Long Term Feeding Tube Placement in Elderly Patients**

This document is the full text of the narration that accompanies the decision aid. The complete decision aid can be found at <http://decisionaid.ohri.ca/decaids.html>.

### **Page 2**

This interactive program has been designed to prepare you for the difficult decision of whether or not to place a feeding tube in an elderly patient. The program was originally designed as a booklet and audiotape. The electronic version of the program will present the pages of the booklet on the left side of your screen and the accompanying text on the right side of the screen. You can move back and forth through the program using the forward and backward buttons on the bottom right hand side of your screen.

The information contained in this program is intended for general interest purposes only. It is not a substitute for professional medical advice or a medical exam. Always seek the advice of your physician or other health care professional before starting any new therapy. Medical information changes rapidly, and while the authors make an effort to update the content on the website, some information may be out of date.

The program was developed by researchers at the Ottawa Hospital, University of Ottawa and Regional Geriatric Assessment Unit. The project was supported by a grant from Physician Services Incorporated.

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This program has been designed to prepare you for a decision about placing a feeding tube in an elderly patient. As you go through the program, you will learn about substitute decision making as well as the advantages and disadvantages of placing a feeding tube in your friend or family member. You will notice that sometimes we refer to the person you are the decision-maker for as "your family member", although we realize that you may not be related.

It will take about 45 minutes to review the program. After reading the text on each page you can either go back to review information you want to review or forward to read the next page. If you have any questions that the program does not answer, please write them down as you go along. You will be able to discuss your questions later with your family member's health care team.

Research studies that support statements in this booklet are referenced by numbers like this:1. The complete list of references is available in a downloadable format at the end of the program.

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This program is for you if ...

- you are the substitute decision-maker for an older patient who is currently unable to make his or her own health care decisions;
  - you need to decide whether the person should have a long term feeding tube known as a gastrostomy tube or a jejunostomy tube. The gastrostomy tube is sometimes known as a "PEG tube" and the jejunostomy tube is sometimes known as a "J-tube."
- 
- This decision aid is not for you if a nasogastric or NG tube is being considered. NG tubes are only used for short periods of time.

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In this decision aid, you will learn about ...

- the reasons why people develop eating and swallowing problems;
- and you will also learn about: feeding tubes, what it means to be a substitute decision maker, the advantages and disadvantages of feeding tube placement, and your treatment options.
- This information can then be used to help you decide whether or not to start tube feeding in your family member.

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Let's begin by discussing why people develop eating and swallowing problems...

Basically, there are four reasons why people might develop these kinds of problems.

- The first is damage to the muscles or nerves that are needed for proper swallowing. Possible causes for this include stroke, Parkinson's disease and Amyotrophic lateral sclerosis, which is sometimes called Lou Gehrig's disease.
- The second reason people are unable to eat independently is because of Alzheimer's disease or other types of dementias.
- The third reason is a blockage of the esophagus. The esophagus is a tube that goes from the mouth to the stomach. If the esophagus is blocked, food will have trouble reaching the stomach. Problems that can result in blockage of the esophagus include cancer or a stricture.
- Finally, there are some patients who have a severe lack of appetite or interest in eating. This group would include patients with a major depression.

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It is important to consider how eating and swallowing problems may affect an older patient and those close to them, such as yourself. These problems may affect you and your family member on a physical, emotional or social basis.

First let us consider the physical issues.

- A person with an eating and swallowing problem is at risk for aspiration. Aspiration is what happens when food or saliva is inhaled into the lungs. Aspiration occurs when a patient is very drowsy or if he has problems with the nerves and muscles, needed for swallowing. The danger of aspiration is that it can cause a lung infection that may need to be treated with antibiotics.
- Eating and swallowing problems may also lead to poor nutrition. Patients with poor nutrition may get weaker, lose weight, become less aware of what is going on and ultimately may not recover as quickly from a sudden illness.
- Finally you may be concerned that a person with an eating or swallowing problem may feel hunger or thirst. However research has shown that patients who are near the end of their lives or who are not very aware, do not experience hunger or thirst.

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Now let's consider the emotional impact of having a family member with eating and swallowing problems.

- Most likely, this person is in this situation because of a serious illness. Naturally, it can be very difficult to come to terms with someone you care about being very ill. It can be even harder to see them not eat enough or worry that they are hungry or thirsty.

Eating is also a very social activity.

- In many cultures it is symbolic of care giving.
- Also helping a person to eat can be a pleasant way to interact with them.
- Unfortunately, some patients may be so sick, they may not be able to eat at all. In these situations, you may feel a loss of this personal interaction. However, other ways of socializing are always possible.

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What is a percutaneous endoscopic gastrostomy tube?

- The short name for this type of tube is a **PEG** tube which is the most commonly used tube for long term feeding.
- The description in this booklet, is mainly about PEG tubes. If your patient is being considered for another type of long term feeding tube called the j-tube, the procedure to place it will differ slightly from the one I will be describing. You should ask your doctor about this.

So, what is a PEG tube?

- It is a tube placed directly into the stomach.
- It is an optional medical treatment.
- "Percutaneous" means through the skin. "Endoscopic" means that a doctor will place a tube with a camera in it, called an **endoscope**, down into the patient's stomach to help guide it to the correct spot. "Gastrostomy" is a word used to describe a procedure where the tube is placed in the stomach through a small hole in the abdomen.

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How is the PEG tube put into place?

- The patient will need to be mildly sedated, but not put to sleep. The endoscope is then placed through the mouth and into the stomach. This can be a bit uncomfortable, but it does not hurt. An endoscope is needed in order to determine the best place to put the tube. The patient is then given a local anaesthetic to freeze the skin. You might have had this type of anaesthetic before if you have ever needed stitches. A small cut is made in the skin and the tube is inserted through the mouth and pulled out through the opening in the abdomen

- This whole procedure should take about 15 minutes, although this may vary.
- Also, if the esophagus is blocked by a growth or tumour, it may not be possible to insert the endoscope through the esophagus. In these situations a more involved surgical procedure will be needed.

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So once the tube is in place, how does the person get their food? This is pretty straightforward.

- liquid food is put into a bag and delivered through the tube into the stomach
- The type of food put through the tube is a commercially prepared liquid designed to provide a balanced diet for the patient. It is something like a milkshake.
- Most patients are fed through the tube at usual mealtimes and the feedings take about an hour. In some cases, especially when the tube is first starting to be used, patients may receive continuous feedings in which the same amount of food is given, but at a slower rate over 24 hours.
- The tube is quite convenient in that it can also be used to deliver medications and water.

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Once the tube is in place, it does require a certain amount of care;

- First of all, care must be given not to pull out the tube. The tube does not fall out easily, but a good tug can make it come out.
- The nurse will check around the tube for leakage and blockage and will make sure that the food is going in properly. The nurse will also clean around the tube at least once a day and check the surrounding skin for any sign of redness, infection or bleeding.
- Usually the tube will need to be replaced within six months to one year. This may be due to general wear and tear, or because of a complication such as blockage or breakage.
- One good thing about the tube is that it is very portable. When the tube is not in use, it will not restrict the patients' usual activities. Also, the tube cannot be seen when the patient is wearing clothes.

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Now that you know a bit about the tube, let's go over what is involved in substitute decision making. Because you have been asked to decide about placement of a tube for another person, you are a substitute decision maker. In other words, substitute decision making is deciding for others who are unable to make their own health care decisions.

A key thing to understand, as a substitute decision maker, is that you are making a decision based on what you think your **family member** would want. This may not necessarily be what **you** would want if you were in the same situation.

Therefore, substitute decision making can be very difficult and emotional.

Who becomes a substitute decision-maker? A substitute decision-maker can be designated in several ways.

- First, when the patient was well he or she may have named someone to make decisions for them if they could not make decisions for themselves. The terms used to describe such a person include "the power of attorney for health care" or "health care proxy".
- If a person has not previously named someone to be their decision-maker, then often it is the next of kin who is designated as the substitute decision-maker.
- If there is no next of kin, then a legal guardian may be appointed for the patient. This is usually done with the help of a social worker in the health care setting.

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What steps are involved in substitute decision making?

There are established ethical and legal guidelines for substitute decision making involving three basic steps.

- The **first** step is to consider any previously expressed wishes that patients made when they were capable of making their own decisions. These previously expressed wishes may have been written down in a living will, which is sometimes called an advance directive, or patients may have mentioned their wishes in a previous discussion with you or others close to them. As a substitute decision-maker, it is your job to try to respect these wishes as much as possible, even if you don't agree with them.
- In many circumstances, a patient may not have previously expressed their wishes. The **next** step would be to consider all you know about the values of the person under your care. From what you know, do you think that she would choose to put in a feeding tube in this situation or not? This is called "substituted judgment".
- If there are no previously expressed wishes, and, for one reason or another you feel you cannot judge what your patient would want, then the **third** step is to consider what is in the patient's best interests. The person's best interests, involves weighing the advantages and disadvantages of each choice and considering how this decision may affect your family member's quality of life. You will learn much more about this later in the decision aid.

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It is very important to know that a feeding tube cannot be placed without the written consent of the substitute decision-maker. This should be an informed decision, and being informed means that the health care provider has explained, to the best of his or her ability, the risks and benefits of tube feeding in this patient's situation.

Now let's consider some of the possible health outcomes from feeding tubes. By "health outcomes", we mean the kinds of things that can happen as a result of having a feeding tube. Another way of thinking about it is: "what are the consequences of getting a feeding tube?"

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We have divided the possible outcomes of tube-feeding into two broad categories: specific complications and general outcomes.

- Specific complications are the complications that occur directly from putting in the feeding tube.
- General outcomes are the reasons that most commonly come up in discussions about feeding tubes, these include; the prolongation of life, and the prevention of aspiration.
- In the next few pages, we will talk about these outcomes so that you can have a better understanding of the advantages, disadvantages and other considerations about tube feeding.

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If you really want to understand what is known about the impact of tube-feeding on the different outcomes, then you need a short course in research design!

Don't panic, it is really quite simple. There are basically three kinds of research studies you need to know about.

The best type, the one with the gold ribbon, is the **randomized trial**. In a study of this kind, whether or not a person gets a feeding tube is decided in random fashion - like the toss of a coin, it is decided by chance. We can be more confident in the results of randomized studies simply because, except for the feeding tube, the patients with tubes should be very similar to those without tubes. Therefore we can assume that any differences in the outcomes between the two groups are mostly because of the feeding tube.

You can see how ethically, it would be a difficult to do a randomized trial of tube-feeding. Therefore, it is important to remember, there **are no** randomized trials of tube-feeding.

The next best type, the one with the silver ribbon, is the **non-randomized trial**. In this kind of study, patients who have chosen to have feeding tubes are compared to patients without feeding tubes. We are still comparing two groups of patients with and without feeding tubes. The difference is that in a randomized study, whether or not someone gets a feeding tube is decided by **chance**. In a non-randomized study, whether or not someone gets a feeding tube is decided by **choice**. We are less confident in the results of a non-randomized study because the two groups of patients may be different in ways that may affect the outcomes. For example, people who are chosen to get a feeding tube may be sicker than those who do not. So we can not be entirely certain that differences in outcomes are due to the feeding tube alone.

The last type of study, the one with the bronze ribbon, is the **case series**. In this kind of study patients with feeding tubes are simply followed over time to see how they do. This is the most common type of study on tube feeding that you can find in medical journals. You can learn a lot from the experience of others who have had feeding tubes. The only problem with case series is that you don't have a group of patients without feeding tubes to compare outcomes.

Now that you have some idea of the different types of studies, let's look at some specific complications of feeding tubes.

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All the information in the table on page 18 is taken from case series.

The first thing to understand when reading over this page is that **everyone is different**: some patients may have no complications; others may have only small or minor complications; and some patients may have more serious complications.

We have tried to summarize the studies for you that have looked at potential complications from the placement of a feeding tube. This may give you some idea of the chances of your family member having a complication. Remember the numbers in the table are just **averages** which vary from patient to patient.

First of all, **infections** may develop from the tube. About 4 in 100 patients will get minor skin infections that can be treated with just some ointment. Others may get a more serious infection of the skin or bacteria in the blood which may be life threatening. Serious infections require intravenous antibiotics. Fortunately, only 1 in 100 patients will get a major infection from putting in a feeding tube.

Placement of the feeding tube may also result in some **minor bleeding** but this happens in less than 1 in 100 patients. **Major bleeding** (so much bleeding that the patient needs a blood transfusion) almost never happens from putting in the tube.

Unfortunately, about 12 in 100 tube-fed patients develop diarrhea or cramping. Thankfully, this is often a temporary problem that is often fixed by changing the type of liquid food or the way it is being delivered. About 9 in 100 patients may get vomiting or nausea. These problems are also usually short-lived.

There may be problems with the tube itself, including dislodgment, blockage or leaking. These minor complications can be treated by flushing out the tube, or possibly by replacing the tube and occur in about 4 out of every 100 tube-fed patients.

On very rare occasions, in less than 1 in 100 patients, the tube will cause a major complication such as a bowel perforation. That means the tube punctured the bowel. This type of complication is life threatening and will require a major surgical procedure to correct it.

Finally, **death**, from feeding tube placement as a result of any major complications occurs in less than 1 in 100 patients.

Please note that the values that are quoted on page 18 are for **PEG** tubes only and may differ slightly for **j-tubes**.

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Now let's look at some of the general health outcomes that are commonly brought up in discussions of feeding tubes.

First, you are probably wondering if the feeding tube **will prolong your family member's life**. You would think the answer to this question is obvious, unfortunately it is not.

Let's look at what the research studies can tell us about feeding tubes and survival.

Remember there are no randomized trials comparing similar patients with and without feeding tubes to see who lived longer. Because of this, there is no straightforward answer to this question of survival.

The non-randomized trials, that have involved patients in nursing homes, have found that tube fed patients do not live longer than similar patients without feeding tubes. However, it is not clear how long these patients would have lived had they never been given a tube. It could be that patients chosen to get tubes were sicker than those not chosen to get a tube.

It is difficult to predict how long your patient would live **with or without** a tube - survival can depend on many factors. Case series have shown that tube-fed patients who are over the age of 85, who aspirate, who are very undernourished, as well as patients with cancer, don't live as long as tube fed patients who don't have these risk factors.

- so if you are concerned about survival, it is important to consider if your family member has any of these risk factors.

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The chart on page 20 can give you an idea of how long you can expect a person with a feeding tube to live. This chart shows you how many out of 100 elderly patients with feeding tubes will still be alive 30 days, 60 days, 6 months and 1 year after putting the tube in.

Please remember that these numbers are averaged from many studies (a mixture of silver and bronze ribbons). It is difficult to know for sure how long any one patient will live. Your patient may live longer than these averages, or may not live as long. It depends on the patient.

However, on average, if you look at the graph, 80 out of every 100 people with a feeding tube will still be alive after 30 days; 74 out of 100 patients will still be alive after 60 days; 54 out of 100 people will still be alive at 6 months, and 44 out of 100 patients who get a feeding tube will still be alive after 1 year.

While you are thinking about this issue of how long your family member is likely to live, remember that **survival** may not be the most important issue for your family member. This will depend on his quality of life, personal values and beliefs. Some people may want to be kept alive as long as possible **no matter what**. Other people may only want to try medical technology if they have a reasonable chance of a **meaningful recovery**.

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Another consideration when thinking about placing a feeding tube is its effect on aspiration.

Let's review what aspiration is.

Aspiration means that the patient inhales or breathes food or saliva into her lungs. You may have experienced aspiration if you ate or drank something quickly and the food went into your windpipe. If you have, you will recall how uncomfortable this is.

Aspiration can also be dangerous because it may cause pneumonia, which is an infection in the lungs.

While many people think that feeding tubes prevent aspiration. The research shows that this is not necessarily true.

Once again there are **no** randomized trials comparing the rates of aspiration in patients with and without feeding tubes.

The **non-randomized** trials comparing patients with and without feeding tubes show that patients with tubes are actually more likely to be aspirators.

The trouble with non-randomized studies is that, it is not clear if getting a feeding tube increases the chances of aspirating, or whether being an aspirator increases the chances of getting a feeding tube.

What is clear, from several case series, is that putting in a feeding tube will not necessarily **stop** a patient from aspirating. More than half of patients in these studies who aspirated before they were given a tube, still aspirated after they were given a tube. On average, 16 out of 100 patients with a feeding tube will aspirate.

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There are a few other things we know about feedings tubes that may be important in your decision;

- Stroke patients with swallowing problems may have better chances of recovery if the feeding tube is placed **earlier** on in their illness rather than waiting a few weeks. Therefore, if your family member has had a stroke it may be more important to make this decision earlier, rather than later.
- Studies have also found that patients who have been totally unaware of their surroundings and totally dependent on others to look after their basic needs for several months, are unlikely to improve whether they get a feeding tube or not.
- Also...tube-feeding may determine what kind of facility he can live in. Certain types of facilities do not have the staff or capability look after a tube-fed patient. If this is important to you, then you need to discuss this with the health care team.
- Finally, some patients with feeding tubes may become agitated and may try to pull the tube out. In this situation, the health care team may suggest restraints or medications to stop the patient from doing this. This means that the patient's arms or legs may be tied down, or medications may be given to sedate her so that she does not pull out the feeding tube. There are risks involved with the use of restraints and sedating medications. As the substitute decision-maker, you should be involved in this decision. This should not happen without your consent!

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Now let's consider the treatment choices for your family member.

Because the person in your care is having eating and/or swallowing problems, the health care team is offering the choice of either;

- supportive care plus the placement of a feeding tube,

or

- supportive care with no feeding tube.

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First let's look at what may be involved in supportive care.

What we are calling "supportive care" involves two things: One...hand-feeding, if possible; and two...other treatments to keep the patient comfortable.

What about hand-feeding?

- It may or may not be safe to hand-feed patients with eating problems.
- Also, some patients **with a feeding tube** may be able to take some food by mouth
- The members of your patient's health care team will decide how safe hand feeding would be. Those involved in this decision may include: a doctor, nurse, dietitian, speech and language pathologist or an occupational therapist.
- They will make this decision based on their experience and may suggest a special swallowing study to see what consistency of food the patient can best tolerate.

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If the health care team has decided that your patient can be safely hand-fed, then who can actually do this?

- Either trained health care professionals (like a nurse, nursing assistant or nursing aide) or family, friends and volunteers can feed the patient.

How are patients hand-fed?

- Not surprisingly, proper feeding techniques are needed to help prevent patients from aspirating.
- One of the nurses can teach family and friends how to safely feed the patient. These techniques include sitting the patient up in bed, choosing food of the right consistency and suctioning the mouth when necessary.
- Keep in mind that hand-feeding a meal can take as long as two hours.

Other treatments are important for supportive care to keep the patient comfortable.

- Some of these treatments include: keeping the patient's mouth moist with a glycerin swab or ice chips; pain control using medications; oxygen for breathing problems; treatment of constipation; spiritual or emotional support; and proper skin care to help prevent skin breakdown and bed sores.

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While you are making this complex decision about whether or not to **start** tube feeding, it is also important to think about what would be involved in the decision to **discontinue, or stop**, tube feeding at a later date.

First there are the technical considerations. It is technically easy to remove the tube. This is done by pulling on it with traction. The tube is designed to be removed this way. It is safe and very nearly painless. In other circumstances, the tube would be cut from the outside and an endoscope would be inserted through the mouth into the esophagus in order to remove what is left of the tube from the stomach through the mouth.

Why would you want to remove it? One reason is that the patient may have improved enough to be able to eat normally. He doesn't **need** the tube anymore.

On the other hand, the patient may **not** have improved and the tube may no longer be in his best interests.

As a substitute decision-maker, it is your choice to make this decision, even though it may be a difficult one. You should discuss this decision with the health care team that has been involved in your patient's care. They may have valuable observations and experience to help you decide what to do.

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You have received a lot of information. So let's go over what we have presented so far about the advantages, disadvantages and other considerations of placement of a feeding tube.

It looks like there are two **advantages** of a feeding tube:

- one, the patient may improve enough to be able to eat again and
- two, the patient will definitely get nutrition.

What about the **disadvantages**? There are three:

- first, there is the risk of complications from having the tube put in. These complications might include major or minor bleeding, infections, tube problems, or death from the procedure.
- The second disadvantage is that the patient may become agitated with the tube
- and the third is that the feeding tube may limit where the patient can receive care.

Finally, there are **other considerations**.

- The research tells us that the feeding tube will not prevent aspiration in those who are likely to aspirate;
- there are certain factors associated with decreased chances of survival in tube-fed patients
- and the feeding tube may or may not improve quality of life.

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Let's put this together. There are **six** proposed steps to help make the decision of whether or not to start tube feeding.

The **first** step: What is your family member's situation? Here are some questions you can ask yourself.

- Is the underlying condition causing the eating problem likely to get better? Is the feeding tube needed to help provide nutrition?
- How concerned are you about specific complications of the feeding tube (such as minor or major tube problems, bleeding, infections)?
- Is the patient likely to become agitated with the tube and need to be restrained to keep it in?

- Will feeding tube placement make a difference as to where the patient can live? -- Is the patient an aspirator?
- Does the patient have any of the factors associated with decreased chances of survival?
- How will the feeding tube affect quality of life?

The **second** step: what would your family member want? This step brings together the issues of substitute decision making.

- Has she ever expressed her wishes (in a living will or previous discussion) about the use of medical technologies like feeding tubes?
- What are his beliefs and values about end-of-life care?
- If she could weigh the advantages and disadvantages what do you think she would choose?
- What do you feel is in your family member's best interests?

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The **third step**: How much are the following feelings affecting you at this time?

- Are you feeling guilty, either for putting in the tube or not putting in the tube.
- Are others **pressuring** you such as family members, the health care team, or friends? These people may be either for or against the feeding tube.
- Do you feel **conflicted** between your personal beliefs and those of your family member.
- Finally, you might worry about a future decision whether or not to continue with the tube.

The **fourth** step: What questions need answering before you can decide?

- You want to make an informed decision. Not all the information you need will be in this decision aid.

The **fifth** step: Who should decide about placing the tube? You are the substitute decision-maker and ultimately your consent will be needed before putting in the feeding tube. However, other family members and people on the health care team may provide some information to help with this decision.

The **sixth** step: Putting this all together, what is your overall leaning about placing a feeding tube in your patient? Are you mostly for, or against the decision, or are you unsure and need more information?

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On the following pages are three examples of made-up, but true-to-life situations of patients for whom a feeding tube is being considered. They are meant to show you how other people might work through the six steps of decision making that we have suggested in this Tube Feeding Decision Aid.

We have also developed a worksheet to help you go through these steps. As you read through the examples, you can get an idea of how to record the facts about your family members' situation and how to weigh all of the factors in order to make your final decision.

Please keep in mind that the examples are not meant to suggest a right or wrong way to make the decision.

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First, let's consider Betty's situation:

Betty had a sudden stroke a few days ago.

#### **Step 1, What is her situation?**

- Her decision maker is unsure if Betty will improve from the stroke, she is not malnourished and has no bedsores so her nutritional status is okay right now. It is not clear if Betty can be hand-fed. Betty is less than 85 years old, is well-nourished now and is not an aspirator, so there is a chance the tube may help her live longer. The small risk of complications from installing the tube would not be a concern for her and she would probably not get agitated from the tube. The type facility would not bother her as long as she was getting good care.
- However, quality of life is important to Betty. She really valued doing most things for herself. If tube feeding would help her regain her independence, she would probably want it.

#### **Step 2, What would Betty want if she were able to decide for herself?**

- Fortunately, this decision maker has had a prior discussion with Betty. In that conversation,

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Betty had said that if she was very sick, she would want "medical technology" if she had a good chance of recovery.

**Step 3** The decision maker is not feeling much guilt, conflict or pressure from others, but she does worry a lot about future decisions regarding continuing with the tube.

**Step 4:** There are questions the decision-maker needs to have answered before she makes her decision.

- How likely is she to recover from the stroke? If she doesn't improve in the next couple of months I doubt Betty would want to continue with the tube. Can we decide to remove it at that point? How hard is it to remove?

**Step 5** Who makes the decision? The decision maker would like to decide with Betty's doctor.

**The Final Step:** After considering everything together, this decision-maker's overall leaning is to put in the tube.

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Now let's discuss a patient in a different circumstance

Harold has had progressive Alzheimer's disease for 8 years.

**Step 1** What is Harold's situation?

The decision-maker has been told that Harold is unlikely to improve. He is very malnourished and has bedsores. Hand-feeding may or may not be possible. His decision-maker noted that Harold has many of the factors that make it unlikely that the feeding tube will impact his survival. Harold often aspirates and the tube will not help this. Although the risk of complications from the tube is small, Harold already is quite sick, and he would not want to add to his problems.

Also... he is likely to get agitated from the tube, and Harold would hate to be restrained.

Finally, one of Harold's only pleasures are visits from family. So it would not be good for Harold to be moved to a facility that the decision-maker could not easily visit.

Harold's major goal would be to stay as comfortable as possible.

**Step 2:** What would Harold want if he could tell us?

Harold did prepare a living will stating that he would not want "medical technologies" to be used if there was little chance of a meaningful recovery, however he did not specifically mention feeding tubes. Based on that, the decision-maker didn't think he would want the tube in his present situation.

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**Step 3.** How is all this affecting the decision-maker?

Harold's decision maker is feeling somewhat guilty because he is worried that not putting in the tube may be like "denying him food". However, if he were in Harold's situation he would not want to be tube-fed so, he does not feel conflicted. He is not feeling any pressure from others nor is he really worried about future decisions.

**Step 4:** In order to reach a decision, the decision-maker would like to ask the following questions.

- Will Harold feel hunger and thirst without the tube?
- Does Harold's current nursing home care for tube-fed patients?

**Step 5,** In this section the decision maker has written "Harold hasn't told me exactly what to do in this situation, so I must decide for him based on what I think he would want. I'll talk it over with his doctor who has known him for a long time".

**Step 6,** After considering everything together, the decision-maker is leaning toward choosing supportive care only for Harold and not placing the feeding tube.

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Let us now look at one final case.

Anne had a big stroke 10 days ago; the doctor said that she may not recover,

### **Step 1** What is Anne's situation?

- Anne is unlikely to improve.
- With respect to nutrition, she is well nourished at the moment and has no bedsores. It is unclear if Anne can be hand-fed safely. Anne has only two of the factors that suggest a feeding tube may not prolong her survival: she is disoriented and she is an aspirator. The feeding tube may not help with the aspiration.
- The small risk of complications from putting in the feeding tube would not be a concern for Anne and she probably would accept the risk of being restrained if she got agitated. She also would accept a change in facilities if necessary.
- In the past three months, Anne has had a good quality of life. Although it is unlikely that she will return to her previous quality of life, her decision-maker is not sure that would matter to Anne. The decision maker is concerned, on the one hand, about respecting Anne's religious beliefs, which are very important to her, and on the other hand about prolonging a poor quality of life for Anne.

### **Step 2.** What would Anne want?

Anne has no living will. However, she once told her decision maker that if she was very sick, she would want all medical care available. Even so, the decision maker is unsure how Anne would feel about having a feeding tube in this situation.

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**Step 3** The decision maker is feeling a lot of guilt and conflict about the decision to tube feed. She is conflicted because she would not choose the feeding tube for herself if she were in Anne's situation, yet she thinks Anne may want it. She wants to respect Anne's wishes.

There also is some pressure from other family members and the decision-maker is worried about future decisions about keeping the tube if Anne does not improve down the road.

**Step 4,** In order to make this decision, the decision maker would like know what would best respect Anne's religious beliefs

**Step 5,** Who should decide? The decision-maker feels that she will decide after talking to the doctor and Anne's pastor, who knows her well

**Step 6. Finally,** after putting it all together, the decision maker stills feels unsure, but is leaning slightly towards putting in a feeding tube.

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Now that you have seen how some other substitute decision makers have filled in their work sheets, you can do the same to help make your decision. Start at step one and work through the six steps.

It might also be helpful to go through the worksheet with other family members or friends who know the patient as well as you do. Once you have filled it in, you can show it to your patient's doctor or other members of the health care team. There may be some questions they would need

to answer before you can complete worksheet, especially regarding your family member's likelihood of recovery.

Please take a few minutes now to complete the worksheet. I hope that you have found the booklet helpful and informative and thank you for listening.

**Note:** In order to print the worksheet on the left, click on the print icon on the top left of the window. Printing using the browser print function will not work in Netscape.